DOCUMENT RESUME

ED 399 755 EC 305 094

TITLE Deaf-Blind Perspectives. Volume 3, 1995-1996.
INSTITUTION Western Oregon State Coll., Monmouth. Teaching Research Div.
PUB DATE 96
NOTE 50p.; For volume 2 issues, see ED 392 184.
AVAILABLE FROM Teaching Research Div., Western Oregon State College, 345 N. Monmouth Ave., Monmouth, OR 97361; telephone: 503-838-8885; tty: 503-838-8821; fax: 503-838-8150; Website: www.tr.wosc.osshe.edu/tr/dbp (also available in alternate formats; free).
PUB TYPE Collected Works - Serials (022) -- Information Analyses (070)
JOURNAL CIT Deaf-Blind Perspectives; v3 n1-3 Fall 1995-Spr 1996

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Adapted Physical Education; Adults; Athletics; Communication Skills; *Deaf Blind; *Educational Strategies; Elementary Secondary Education; Family Needs; Higher Education; International Organizations; *Intervention; Networks; Parent Associations; Preservice Teacher Education; Professional Development; Recreational Activities; Services; Simulation; Skill Development; Social Support Groups
IDENTIFIERS Individuals with Disabilities Education Act; Reauthorization Legislation; Utah

ABSTRACT

These three newsletter issues present feature articles and resources on individuals with deaf-blindness. The following articles are included: (1) "Current Status for Reauthorization of IDEA" (Joseph McNulty); (2) "Utah Enhances Services for Children Who Are Deaf-Blind" (Paddi Henderson and John Killoran); (3) "Families and Support Networks" (Robert W. Moore and Cherry W. Moore); (4) "An Introduction to the International Organizations and Literature Related to Deafblindness" (Betsy L. McGinnity); (5) "Personnel Preparation: Past, Present, and Future Perspectives" (Barbara A. B. McLetchie); (6) "Simulation Exercises To Help Stimulate Discussions about Communication Strategies Used with Students Who Are Deaf-Blind and Developmentally Delayed" (Jennifer White and Lyle T. Romer); (7) "Free To Be Me" (Joann Twitchell), a personal narrative of a parent of two children with Usher Syndrome; and (8) "Adapting Games, Sports, and Recreation for Children and Adults Who Are Deaf-Blind" (Lauren J. Lieberman). (Most articles contain references.) (CR)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)
☒ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Deaf-Blind Perspectives. Volume 3. Numbers 1-3.

ED 399 755

EC305094

12297

Deaf-Blind Perspectives

Volume 3, Issue 1 Fall 1995

Current Status for Reauthorization of IDEA

Joseph McNulty
Helen Keller National Center

As this issue of Deaf-Blind Perspectives goes to press, the process of re-authorizing the Individuals with Disabilities Act (IDEA) is far from complete.

Last month the Committee on Economic and Educational Opportunities circulated the House of Representatives' draft for reform of IDEA. Part D of the Draft "IDEA Improvement Act of 1995" would consolidate the current fourteen special purpose (discretionary) programs funded in FY 1995 under IDEA into one new Part D, National Activities to Improve Education of Children with Disabilities.

If one attempts to identify where the existing discretionary programs will be placed within the proposed Act, some are rather apparent. For example, Personnel Training (Part D, Section 631 and Section 632 of the current law) will fall under Section 678—National Activities in Professional Development. The current Parent Training Program is covered by Section 673 in the proposed bill—Technical Assistance for Parent Training and Information Centers. Other discretionary programs such as Instructional Media (Part F, Section 651) and Technology, Educational Media, and Materials (Part G, Section 661) will be included in the new legislation in Section 679—Technology Development and Section 680—Educational Media Services.

This is clearly not the case for the Services for Deaf-Blind Children and Youth! Section 699A of the proposed bill calls for minimum funding requirements for several categories of children, including "$12,832,000 to address the educational, related services, transitional, and early intervention needs of children with deaf-blindness."

But what portion of the money will be used to fund Parent Training and Information Centers? How much of this funding will be used to support National Activities in Professional Development? If a grant awarded under Technology Development carries out research on the development of technology for children who are disabled that may include children who are deaf-blind, does some of the grant money come from the $12.8 million set aside in Section 699A?

And who determines how any or all of this money is spent? Who identifies the priorities? Who monitors the programs receiving these funds? The coordinated efforts across program management, research, systems change, technical assistance and information dissemination that have been achieved under the existing Deaf-Blind Children and Youth program will be significantly reduced.

A second concern with the proposed House bill is that Section 699A also includes the statement, "If the total amount appropriated to carry out this part for any fiscal year is less than $254,034,000, the amounts listed in subsection (a) shall be ratably reduced."

If the recently passed House appropriations bill were to be adopted by the Senate, the amount for the new Part D would drop from the current $254,034,000 to $92,491,000, a reduction of approximately 64%. Under the proposed formula, Deaf-Blindness would received less than $4.7 million. The Senate appropriations mark-up is scheduled for mid-September.

In This Issue

Current Status for Reauthorization of IDEA .. 1
Joseph McNulty

Utah Enhances Services for Children who are Deaf-Blind 3
Paddi Henderson
John Killoran

Request for Proposals Announced 6

Families and Support Networks 7
Robert W. Moore
Cherry W. Moore

An Introduction to the International Organizations and Literature Related to Deafblindness 12
Betsy L. McGinnity

Personnel Preparation - Past, Present and Future Perspectives..... 15
Barbara A. B. McLetchie

BEST COPY AVAILABLE

The Senate has not begun its deliberations on IDEA although the Disability Policy Subcommittee of the Labor and Human Resources Committee has announced its intention to have a first draft by September 18 and a full committee report by October 25.

A number of things must take place before IDEA is enacted. The House is in the process of preparing a second draft of its proposed bill and will present it to the full committee sometime in September. When the Senate's bill is approved, the two bodies will meet to iron out any differences and agree on a final version which will go to the President for his signature.

While we in the field of deaf-blindness are primarily concerned with the Services for Deaf- Blind Children and Youth program, the attention of the legislators, educators and the disability community are on other matters. Major disagreements surrounding issues such as discipline, attorneys fees, the resolutions of disputes on appropriate services and placement, and the funding formula are generating a great deal of debate. There is a good chance that the legislation may not be finalized until the end of the calendar year.

It is critical that we all monitor the proceedings closely since this bill will determine the educational services to be provided to every child who is deaf-blind in this country.

If you have any questions on concerns, do not hesitate to contact the

National Coalition on Deaf- Blindness

(617) 972-7221 or
(516) 944-8900, ext. 270.

Deaf-Blind Perspectives
Volume 3, Issue 1
Fall 1995

❖❖❖❖❖❖❖❖

Executive Editor
Bud Fredericks
Teaching Research

Managing Editor
Bruce Bull
Teaching Research

Consulting Editors

Harry Anderson, florida School for the Deaf and Blind; Bruce A. Dalke, Teaching Research; June Downing, California State University – Northridge; Joyce Ford, Parent; Jay Gense, Mid Oregon Regional Program; Marilyn Gense, Oregon School for the Blind; Karen Goehl, Indiana Deaf-Blind Project; Richelle Hammett, University of Maryland; Barbara A. B. McLetchie, Boston College; Kathy McNulty, Helen Keller National Center; Robert Moore, parent; John W. Reiman, Teaching Research; Marianne Riggio, Perkins School for the Blind; Art Roehrig, Gallaudet University; Rosanne Silbrman, Hunter College.

Production Editor
Randy Klumph
Teaching Research

❖❖❖❖❖❖❖❖

Deaf-Blind Perspectives considers all unsolicited manuscripts and employs an anonymous review process. Manuscripts should adhere to *American Psychological Association* standards. *Send both a printed copy and a disk copy (preferably DOS format) to:*

Deaf-Blind Perspectives
Teaching Research Division
345 N. Monmouth Ave.
Monmouth, OR 97361
(503) 838-8403
TTY (503) 838-8821
fax (503) 838-8150

Utah Enhances Services for Children who are Deaf-Blind

Paddi Henderson
TRACES Western Region

John Killoran
Utah State Office of Education

The original manuscript contained language established by the Utah Legislative Task Force that referred to children with "dual sensory impairments." That language has been changed to "children who are deaf-blind" in keeping with the editorial policy of Deaf-Blind Perspectives.—ED

Over the past nine months Utah parents of children who are deaf-blind have lobbied the Utah state legislature for funding for one-on-one intervener services for children who are deaf-blind, birth to five years old. Assistance was provided by the Utah State Office of Education, the SKI*HI Institute, the Utah Project for Children with Dual Sensory Impairments (the Utah 307.11 Deaf-Blind Project), and the Legislative Coalition for People with Disabilities. This lobbying effort resulted in a two-fold piece of state legislation: First, a one-time $193,500 appropriation was granted for direct intervener services for children who are deaf-blind. Second, a directive was included to develop a legislative task force to design a state plan to address the needs of all individuals, birth through age 21, who are deaf-blind.

The new legislation came about because of the immense dedication of several people. It became clear, during the legislative process, that others concerned about funding for services for individuals who are deaf-blind might benefit from learning about the experience of these parents and professionals. Although many different individuals could provide diverse views on the process and the anticipated impact of this legislation, two primary perspectives were sought for this article: that of a parent of a child who is deaf-blind and that of a representative of the Utah State Office of Education. Both of these individuals were highly instrumental in gaining the interest and support of the Utah State Legislature.

Interview with Stephanie Carlson

Stephanie Carlson is Travis' mom. Travis is a three year-old boy who is deaf-blind.

Q: What was the catalyst for this recent state legislation specific to services for children who are dual sensory impaired?

The SKI*HI Institute informed me that the grant for the Intervener Program for children, birth to three, who are deaf-blind was ending and no other funding had been obtained. Since this program has been such an important part of my son's life, I knew that it could not end. In fact, since it had not been promoted for children aged 5–21, I felt that needed to happen also. I asked the Legislative Coalition for People with Disabilities what needed to be done to obtain state funding for deaf-blind intervention services.

A group of Utah parents of children who are deaf-blind then met to discuss what services our children need that are not available in the state. With the help of several agencies we put together a plan of action and a financial request.

If I could recommend anything to other groups considering requesting state funding, it would be to plan far enough in advance to begin the legislative process at least six months prior to the beginning of the legislative session. We began this process only two months before the session. We could have saved ourselves many headaches if we had started earlier. I really appreciate our Legislative Coalition. They walked the parents through the process, putting them in contact with the appropriate people to move the process along.

Q: Why was this process initiated?

Again, the primary motivation was the fact that the Deaf-Blind Intervener Program would soon be without funding. My son, Travis, if put in a classroom in a public school or at the Utah Schools for the Deaf and the Blind, would not be able to participate without the help of a person specially trained to provide him with the information which he can't get through his eyes and ears. It is imperative, especially for children more severely impaired, to have a person that understands deaf-blindness *and* all of the other needs including the specific communication, educational, and medical needs of that one child.

The vast majority of children who are deaf-blind are not at the Utah Schools for the Deaf and the Blind. They are in the public school system where few teachers have been specifically trained in deaf-blindness. That is why the parents pushed for this legislation—to get deaf-blind specific services and training.

Q: What role will parents play in designing the State Plan for all educational services for children who are deaf-blind?

Parent involvement is essential and priceless. There are eight parents out of a total of 32 members on the Legislative Task Force. The parents involved represent all age groups of children from preschool through adulthood. Together we are supplying information about what our children really need at all different ages.

The service providers on the Task Force have different backgrounds and different specialities. Some of them have training in deaf-blindness and some don't. As par-

Basic Definition of an Intervener

An intervener is specially trained to provide clear and consistent sensory information to an individual who is deaf-blind, compensating for both vision and hearing loss in such a way as to facilitate and enhance learning and interaction with the physical environment and with society. An intervener acts as the eyes and ears of the individual who is deaf-blind, making him or her aware of what is occurring and attaching language and meaning to all experiences. An intervener intercedes between the individual who is deaf-blind and the environment in such a was so as to minimize the effects of multisensory deprivation, and to empower the individual to have control over his or her life.

ents, our specialty *is* our child. That's why our input is important.

I think all of the Task Force members are very sensitive to the parents' needs and concerns. It has been an exciting, positive experience to see this many people come together for one purpose and have it work so well.

Q: As a parent, what are the most critical long-term issues which need to be addressed through the State Plan?

Communication is the number one priority. We must provide a means for individuals who are deaf-blind to learn to communicate and to communicate appropriately in their natural environments, especially in school. Some children may need one-on-one interaction with an intervener to communicate. Other children may learn to communicate well using an alternative system such as a communication board. The key is that each child needs an *individualized plan* in order to receive an appropriate education.

The second issue, which is a major one for our family, is the need to integrate all of a child's services to accomplish the above priority. This is especially important with children who are severely, medically fragile. Travis is a technology dependent child. He has a trach and would be at risk of dying without a medically trained person with him. I believe his medical, educational, deaf-blind, and other related services can be integrated and delivered wherever the educational process is taking place.

The final issue is that of training. There are just not enough people trained in dual sensory impairments to provide the necessary services. The Task Force will design ways for Utah to overcome this problem.

Q: How will the State Plan system of services for children who are deaf-blind differ from the current system?

Although the development of the system is not complete, I can tell you the parents' goals for the State Plan.

All children who are deaf-blind will have access to direct intervention services which are individualized to meet the unique needs of each child and his or her family. The services may be delivered at school, at the local park, in a nursing facility—wherever the child is located.

The entire system of medical, educational, deaf-blind specific and other related services will be smoothly integrated for the benefit of all children and families. Obtaining and coordinating the delivery of all of a child's services will no longer be a nightmare for parents.

And finally, training to provide direct intervention and technical assistance services for children who are deaf-blind will be available to the most appropriate person for the child. Opening the training up to a variety of individuals will help integrate services and decrease the number of service providers in a child's life.

Q: From a parent's perspective, what impact do you hope this legislation will have on your child and family and on other Utah children who are deaf-blind and their families?

I think my hopes can accurately be extended to all of Utah's children. My vision is that when a child is deemed to need intervention services, the most appropriate services for that child will be available and provided by a person trained in dual sensory impairments. I strongly believe that intervener services have had a very positive impact on Travis' life. I hope that through this legislation he will have these services available to him as needed from age 5–21 and even beyond.

I've seen that it is often the parents that are most assertive that are able to get services for their child. I don't want children to do without services because their parents are not assertive enough, or are too tired, or have just met their limit and have no fight left. Getting essential services should not be a battle. I hope we can create an integrated system which provides the services needed in a family-friendly manner.

Finally, the State Plan will establish the framework for families and professionals to assist Travis and other individuals who are deaf-blind to build a life full of the supports and services needed to make their lives meaningful and rich with experience and fun!

Interview with Dr. Stevan J. Kukic

Dr. Stevan Kukic is the Director of At Risk and Special Education Services for the Utah State Office of Education. He is the chair and facilitator of the Legislative Task Force.

Q: Why was this process initiated?

Actually, there were several concurrent events which resulted in the initiation of the legislation. First, the Utah Project for Children with Dual Sensory Impairments (Federal 307.11 Grant) can no longer use federal dollars to fund direct services to children who are deaf-blind. Utah is now mandated to provide direct services to all children with disabilities, birth through 21, through Part H and Part B. Second, the SKI*HI Institute at Utah State University was notified that the federal grants for several technical assistance and direct service projects related to the provision of services for children who are deaf-blind were coming to an end.

The Utah State Department of Health and the Utah State Office of Education had been working with the SKI*HI Institute on securing an alternative mechanism for funding for approximately one year; however, the loss of federal funds resulted in the need for immediate fiscal support to continue the direct services which were being threatened.

Q: The legislative bill clearly defines the membership of the Task Force. Why were these particular agencies selected and how will they contribute to the design of the State Plan?

Services to children who are deaf-blind and their families should not be restricted to the six-hour educational days in which most children are involved. Meeting the intense needs of many infants and students requires substantial collaboration between agencies such as the State Department of Health, Medicaid, Human Services, and others included on the Legislative Task Force. The state of Utah is committed to what we have titled the FACT Initiative. This initiative, "Families, Agencies, and Communities Together," guides multiagency collaborative activities between state agencies, families and other community organizations to enhance services to children at risk, including those who are disabled. Through collaboration we are increasing the effectiveness of what we do.

Other agencies and organizations are included on the Task Force for obvious reasons. Individuals who are deaf-blind, parents, and representatives from many

agencies including the Utah Schools for the Deaf and the Blind, local school districts, the Legislative Coalition for People with Disabilities, and the SKI*HI Institute are considered essential and equal partners on the Task Force. Their input, expertise, and efforts are essential in the development of a State Plan, which is our true goal, in contrast to a "state office" or "agency" plan.

Q: The Task Force is on a fairly short time line. What process will be employed to accomplish the sizable task of designing the State Plan?

The Utah State Office of Education has undertaken several major planning initiatives in recent years. In 1991, a strategic planning team of parents, educators, legislators, key decision makers and stakeholders in Utah's special education service system was organized for children and families who are disabled. The document developed by this team, the "Utah Agenda for Meeting the Needs of Students with Disabilities," has become the guiding force for policy development, legislative activities and funding and the restructuring of educational services for Utah's 55,000 students who are disabled.

The strategic planning model used for the development of the Utah Agenda and other strategic planning activities, (Cook, 1989; Gibbs, 1989) is also being used by the Legislative Task Force. This model relies heavily on the concepts of good faith planning and consensus-based decision making. Task Force members have equal opportunities as consumers, parents, professionals, and advocates to provide input and to feel ownership in the resulting State Plan. The collective desire of the group to design a state plan which will be accepted and funded by the state legislature during the 1996 session also provides the incentive to proceed in a timely manner.

Q: Will the Task Force and the resulting State Plan address all needs affecting individuals who are dual sensory impaired or only educational needs

The intent of the legislation is for the development of a state plan specifically addressing the educational needs of children who are deaf-blind. However, the consensus of the Task Force at the initial meeting was that the educational needs of a child should be considered within the context of his or her whole life. In addition, the group agreed that concern should also be given to the needs that children will encounter as they become adults.

The final State Plan and accompanying budget request which will be proposed to the State Board of Education and the Legislature will outline the educational services to be developed and provided specifically for children, birth through 21, who are deaf-blind. It will also define the means by which all other special education and noneducational services can be accessed and integrated to meet the individual needs of children who are deaf-blind.

Q: How will the State Plan system of services for children who are deaf-blind differ from the current system?

Without having a finalized State Plan, the answer to this question may still be ambiguous. The Task Force has accepted the previously developed objectives and strategies of the state deaf-blind project as the initial concepts to be included in the State Plan. These objectives and strategies focus on the provision of technical assistance for children birth through 21 who are deaf-blind and their families and service providers. To enhance all technical assistance services, three strategies overlie all of the objectives: (a) to institutionalize a centralized statewide system for all deaf-blind technical assistance services; (b) to use a transdisciplinary approach to service development and delivery; and (c) to provide categorical (deaf-blind specific) technical assistance in noncategorical and inclusive settings.

Key components that were not included in the state deaf-blind project are the provision of direct services to children who are deaf-blind, including intervener services, and the identification of a specific funding source for these services. The major work of the Task Force will center on designing the objectives and strategies to include both of these elements in the State Plan.

Q: From the perspective of a State Director of Special Education, what impact will this legislation have on Utah's children who are deaf-blind. Do you foresee any impact on children in the state who have other severe disabilities?

The concept of services for children who are deaf-blind envisioned by the Task Force is consistent with the concept envisioned for services for *all* students who are disabled in the state of Utah. That is, direct and technical assistance services, support systems, and funding will be provided to allow children to participate in the inclusive home, educational, and community environments which are most appropriate to meet their individual needs.

This legislation has increased the awareness of deaf-blindness, as well as other severe disabilities. It has highlighted the need for a continued emphasis on the provision of categorical services for children who are deaf-blind, regardless of the setting, inclusive or categorical, in which they are served. Although the Task Force will be requesting legislative funding for deaf-blind services, this legislation will assist in developing the coalitions, partnerships, and support systems needed for a unified advocacy for future funding of all special education services.

Finally, through this legislation, the collaborative efforts of many different individuals and agencies will be focused on the single most important goal: to provide the most appropriate services to meet the unique needs of each child who is deaf-blind. This will happen. In Utah, collaboration is not just a buzz word but a reality.

A great deal has happened since the Utah Legislature approved this legislation specific to individuals who are deaf-blind. The Legislative Task Force began development of the Utah State Plan in May 1995. Since that time five objectives with supporting strategies have been agreed upon. These five objectives are

Objective 1: Consistent intervention services will be developed, implemented and evaluated to meet the unique communication, developmental, academic, social and vocational needs of each individual (birth through 21) who is deaf-blind and his or her family.

Strategies for this objective include the provision of deaf-blind specific services such as interveners, trained interpreters, orientation and mobility specialists and assistive technology devices and services. All families and service providers will have access to a deaf-blind specialist who will facilitate the acquisition and delivery of direct and technical assistance services.

Objective 2: A unified statewide system of coordinated and collaborative technical assistance services will be developed, implemented, and evaluated to enhance the transdisciplinary delivery of the full array of direct services.

Strategies for this objective include the development of a centralized system which can be easily accessed by all families and service providers. This will help eliminate the confusion and frustration encountered when making numerous phone calls while searching for information or services.

Objective 3: Training needs specific to families and service providers of children who are deaf-blind will be incorporated into the state's Comprehensive Interagency System of Personnel Development.

Strategies supporting this objective will focus on expanding pre-service training and ongoing inservice and mentor training programs.

Objective 4: A public awareness system that promotes family-centered services will be developed, implemented and evaluated.

Objective 5: Adequate and equitable funding for implementation of the State Plan will be achieved using a unified advocacy approach in conjunction with the Legislative Coalition for People with Disabilities.

These objectives represent the consensus of the task force and serve as the framework for the development of the State Plan. Detailed action plans to support each of the objectives and strategies are currently being developed. The budget for the legislative funding request is complete and includes the request for state funds, as well as a matrix showing the collaborative fiscal commitment of many different agencies within the state. It is important to know that many of the specific strategies and action plans developed are or will be implemented and funded through these collaborative commitments. The State Plan and funding request will be submitted to the Utah State Board of Education for inclusion in the Education Budget for 1996–97. Legislative acceptance and funding of the State Plan as the directive for statewide services for all children who are deaf-blind is the desired outcome of this endeavor. How will this outcome help children? All Utah children who are deaf-blind, their families, and service providers will have access to direct and technical assistance services which are designed specifically for individuals who are deaf-blind. An individual's services will be coordinated through a service coordinator with knowledge of deaf-blindness and will be delivered in the most appropriate setting for that individual. This legislative funding will allow for consistency and continued enhancement of services for all children who are deaf-blind within the state of Utah.

References

Gibbs, R. (1989). Action team leader's guide. Austin: Cambridge Management Group, Inc., Texas Association of School Boards.

Cook, B. (1989). Strategic planning for America's schools. Austin: Cambridge Management Group, Inc., Texas Association of School Boards.

Request for Proposals Announced

The U.S. Department of Education, Office of Special Education Programs, Services for Children with Deaf-Blindness Program announced requests for proposals in three priority areas. (See August 10, 1995 Federal Register pp. 40968, 40970-71).

Absolute Priority 1. *Technical Assistance for Children, Adolescents, and Young Adults Who Are Deaf-Blind*

Estimated Size of Award: $1,600,000
Estimated Number of Awards: 1
Project Period: 60 months
Application Deadline: October 25, 1995

Absolute Priority 2. *Demonstration Projects for Children with Deaf-Blindness*

Invitational Priority: The Secretary is particularly interested in applications that meet the following invitational priority, but an application that meets this invitational priority does not receive competitive or absolute preference over other applications.

- Improve instructional techniques that enhance communication skills, including use of augmentative devices and assistive technology;
- Improve social skills, including social interaction;
- Improve independent living skills, including self determination, mobility, and other community living skills;
- Improve recreation and leisure skills; or
- Improve more traditional skills, including academic achievement and transition and employment skills.

Estimated Range of Awards: $130,000 to $135,000
Estimated Average Size of Awards: $133,000
Estimated Number of Awards: 5
Project Period: 36 months
Application Deadline: October 25, 1995

Absolute Priority 3. *National Clearinghouse for Children Who Are Deaf-Blind*

Estimated Average Size of Award: $325,000
Estimated Number of Awards: 1
Project Period: 36 months
Application Deadline: November 1, 1995

Application materials will become available on September 11, 1995.

Contact: Robin Buckler, US Dept of Education, 600 Independence Ave SW, Room 4617 Switzer Bldg, Washington, DC 20202-2732; 202/205-9844.

Families and Support Networks

Robert W. Moore
College of Medicine, University of Kentucky

Cherry W. Moore
Interdisciplinary Human Development Institute, University of Kentucky

Introduction

Families of children who are deaf-blind, like people who are deaf-blind themselves, (Mar, 1992) are vulnerable to avoidance, social isolation, and exclusion from social interaction. A recent review of the literature revealed that there is a major need for "more attention in professional writings on the needs and perceptions of parents of individuals who are deaf-blind" (Fredericks, 1992). As support networks for families of children who are deaf-blind become stronger, they can help meet this need by conducting research on their participating families under their own auspices.

The uncommon combination of disabilities associated with deaf-blindness means that there will often be a high level of geographic separation among families of children who are deaf-blind. In Kentucky, for example, with a population of 3.7 million, there are approximately 140 families with children listed in the Kentucky Deaf-Blind Registry maintained by the state's federally funded 307.11 project (Leatherby, 1993). These families are scattered among 120 counties across the state, with several counties having only a single family with a child who is deaf-blind.

Deaf-blindness, that may include other disabilities, presents families with huge caregiving challenges. These challenges often limit a family's mobility, with the result that some families are unable to participate in normal community activities. Some even find it difficult to attend events such as parent-professional conferences which are explicitly designed to address their interests.

Unfortunately, our society continues to stigmatize both individuals who are disabled and their families. This, in combination with the distances and barriers to mobility described above, place families of children who are deaf-blind at higher risk for social isolation. In one survey in which mothers of children who are deaf-blind were asked to name three things that would have helped them to care for their children, the most frequently volunteered response was "more family support" (Vadasy & Fewell, 1986). It is partially in response to such sentiments that family support networks are being encouraged, though what constitutes family support is not universally agreed upon.

One family support effort in Kentucky is the establishment of PCDSI.

PCDSI is a new organization whose mission is to provide information and support to families of children who are deaf-blind.

PCDSI emerged from a series of annual retreats sponsored by the Hilton-Perkins National Project and Kentucky's 307.11 project, known within the state as the Deaf-Blind Intervention Program (DBIP). The support network was informally organized in 1992 and became incorporated with designation by the Internal Revenue Service as a tax-exempt organization in 1993. PCDSI now plans the annual family retreat, distributes a newsletter, represents families in disability coalitions, holds events to raise public awareness, engages in advocacy activities, and has obtained funding to develop a telecommunications network among its participating families. Membership in PCDSI is loosely defined, with families of 69 (49%) of the 140 children on the Kentucky Deaf-Blind Registry having contacted the organization or participated in some of its activities as of late 1993. Information about PCDSI is distributed by the DBIP staff to all families in Kentucky who have a child on the Deaf-Blind Registry. Due to concerns with confidentially, however, all participants in PCDSI are self-referred to the support network.

The purpose of this report is to describe the results of a survey of Kentucky families of children who are deaf-blind which was conducted under the auspices of Parents Confronting Dual Sensory Impairment (PCDSI).

The survey addressed several topics, including support networks, the state's deaf-blind intervention program, services from other agencies, computers and telecommunication, and family characteristics. This report is limited to a presentation and discussion of the findings regarding family characteristics and family support networks.

Methods

A proposal and draft questionnaire were submitted for approval to the Institutional Review Board for the protection of human research subjects at the University of Kentucky. The procedures and questionnaire were pretested and revised to ensure confidentiality and reduce the duration of the interviews.

A telephone survey was conducted by experienced, trained, supervised interviewers. PCDSI's directory of self-referred families of children with dual sensory impairment provided the list of households to be contacted. Of approximately 140 families in Kentucky with a child on the confidential Deaf-Blind Registry at the time of the survey design, 69 (49.2%) were included in this directory. Of these 69, interviews were not conducted with 16 because 7 were found to have no telephone or a disconnected number, 3 could not be reached after 6 or more attempts, 2 had children who were deceased, 2 refused, 1 parent was hospitalized, and 1 parent said the child was not visually impaired. Of the remaining 56 families who could be reached, 1 completed questionnaire

was lost during data processing. These respondents represented 76.8% of the families listed in the PCDSI directory and approximately 38% of the total number of families on the confidential Kentucky Deaf-Blind Registry. Some questions were not asked of some respondents because predetermined skip patterns in the questionnaire specified that they should not be asked about topics of which they had already expressed no knowledge.

Questionnaire responses were reviewed by supervisors for completeness, accuracy, and clarity. Repeat calls were made where necessary for additional information or clarification. Responses were coded and the data entered and verified for electronic processing. The analysis in this paper uses descriptive statistics only.

Findings

At the beginning of the interview, respondents were assured that their responses would be treated confidentially and reported anonymously, and that the interview would take "about 10 minutes." The actual mean duration of the completed interviews was found to be 17.8 minutes (standard deviation = 6.5), with a median of just under 15 minutes and a range from 10 to 50 minutes.

Interviewers rated the respondents' understanding of the questions as excellent or good for all but 2 respondents (96.3%). The respondents' interest in the survey was very high or above average for 90.5%. Only 1 in 10 (9.4%) revealed any resistance to the questions at any point during the interview. Table 1 shows some characteristics of the participating families.

The most important benefit of family support group activities was hearing stories or receiving information on successful interventions that had helped children who are deaf-blind.

Respondents were asked to rate the importance of various benefits they might experience as a result of activities of a parent support network. The results of these ratings are shown in Table 2. All of the benefits listed were highly valued by the respondents, with half (47.1%) or more rating each of the items as "very important" to them. Nevertheless, both the mean rating and the percentage rating each benefit as "very important" revealed an ordering. The item ". . .information on what has been successful helping children with dual sensory impairment" was the most highly valued. Second most important was ". . .referral to agencies which might be helpful." After these two information-related benefits came friendship, training and participation in advocacy, and emotional support.

Respondents were asked several questions about the quality of their experiences with PCDSI. The responses are shown in Table 3. Although all of the families had been self-referred to the family support network, 30.2% didn't recognize its name. One-third (32.1%) had heard of PCDSI through "other" professionals, primarily special education teachers. Only small proportions had heard of the organization from other parents or from the state's Deaf-Blind Intervention Project. The newsletter was rated as very useful by 17.0%. PCDSI was perceived to be more helpful in providing information than it was effective in providing support. Half of the respondents (50.1%) were very interested in future involvement in the support network.

Discussion

This survey elicited a high response rate from the families we were able to contact. These respondents, however, are probably not representative of all of the families in Kentucky who have a child who is deaf-blind, even though they make up a substantial part of that population. In particular, it seems that families with young children (less than six years old) may be underrepresented in this set of respondents. Respondent interest in and understanding of the survey was judged by the interviewers to be quite high.

The most important benefit of family support group activities was hearing stories or receiving information on successful interventions that had helped children who are deaf-blind. Such stories not only provide information and direction to families, but also offer hope that good outcomes can be achieved from interventions on behalf of their children. The second ranked benefit, referral to agencies, indicates the instrumental or task orientation of families. Third ranked was friendship, which reveals the need families have for networks to overcome the isolation that can accompany their child's disabilities.

PCDSI was familiar to most, but not all of the respondents. PCDSI was judged to be more successful in supplying information than in providing support. A large majority of these respondents were very or somewhat interested in future involvement with this parent support network. PCDSI is still a new organization, being led for the most part by its original board members and officers. As leadership turns over it is expected that participation will be broadened and the proportion of families who are familiar with the group will increase, as will the benefits to these families. PCDSI should attempt to maximize the opportunities for families to share their stories with one another and to involve professionals in giving accounts of successful interventions for children who are deaf-blind.

Support networks initially are dependent upon professionals to make their existence known to poten-

tially interested families. Due to concerns over confidentiality, families with children who are deaf-blind will usually not be known to the volunteer support network until the families initiate contact, usually with the mediation of professionals. The federally funded 307.11 deaf-blind intervention programs have a key role to play in mediating such contacts. To strengthen future research efforts by family support networks, collaborative agreements with 307.11 programs should be made so that a state's entire population of families with children who are deaf-blind can be included in such studies. Arrangements can be made that protect the confidentiality of families who are not participants in the support network, while still giving them an opportunity to respond to the survey.

This survey demonstrates that family support networks can take initiative in gathering useful information from their participating families. Support networks in other states can conduct their own surveys to discover family perceptions of the most desired or useful activities in their states.

Families of children who deaf-blind want information and support from their networks. As one parent commented, "Give me information. With information I can empower myself."

Acknowledgment: This research was supported by Parents Confronting Dual Sensory Impairment, Inc., and by a grant from the Interdisciplinary Human Development Institute at the University of Kentucky.

Table 1. Characteristics of the responding families: Numbers and Percent.

Variables	Values	n	%
Sex of Respondent	Female	43	81.1
	Male	10	18.9
Age of Respondent	<41	18	34.0
	41-50	26	49.0
	51+	9	17.0
Marital Status of Respondent	Single	11	20.8
	Married	42	79.2
Years of Schooling of Respondent	<12	9	17
	12	21	39.6
	13-16	14	26.4
	17+	9	17.0
1993 Total family income, before taxes	000	7	13.2
	10,000-20,000	15	28.3
	20,000-30,000	13	24.5
	30,000-40,000	6	11.3
	40,000+	9	17.0
	refused	3	5.7
Residential stability: "What do you think are the chances you will be living at this address five years from now?"	Very high	35	66.0
	Moderately high	7	13.2
	About even	6	11.3
	Moderately low	2	3.8
	Very low	3	5.7
Sex of child with DSI	Female	25	47.2
	Male	28	52.8

Table 1 continued Variables	Values	n	%
Age of child with DSI	<6	5	13.2
	6-18	29	54.7
	19+	17	32.1
Interviewer's rating of respondent's understanding of the questions	Excellent	34	64.2
	Good	17	32.1
	Fair	1	1.9
	Poor	1	1.9
Interviewer's rating of respondent's interest in the survey	Very high	35	66.0
	Above average	13	24.5
	Average	5	9.4
	Below average	0	0.0
	Very low	0	0.0
Interviewer's perception of resistance in the respondent at any point in the survey	No	48	90.6
	Yes	5	9.4

Table 2. Relative importance of benefits of support network activities: means, Standard Deviations, and Percents.

Interviewer's Introduction: "You may know that there is a national effort to create support networks for families who have children with dual sensory impairment. I'm going to read several activities that a family support group might conduct. For each, tell me how important it is to you by saying whether it is...[1=] very important; . . .[2=] somewhat important; . . .[3=] slightly important, or; . . .[4] not important at all. For example, how important to you is it for a family support network to provide you with. . ."

Benefit	Mean	Standard Deviation	% Very Important
. . . information on what has been successful helping children with dual sensory impairment	1.09	0.30	90.6
. . . referral to agencies which might be helpful	1.26	0.56	77.4
. . . friendship	1.30	0.54	73.6
. . . advocacy training and participation	1.34	0.48	66.5
. . . emotional support for your family	1.48	0.73	63.5
. . . training and support using computers	1.68	0.98	60.4
. . . social gatherings	1.75	0.85	47.1

Table 3. Perceptions of a statewide family support organization in Kentucky: Numbers and Percent.

Interviewer's Introduction: "You may also know that there is a newly-formed group in Kentucky called Parents Confronting Dual Sensory Impairment, or PCDSI, for short. PCDSI's mission is to provide information and support for families of children with dual sensory impairment."

Questions	Responses	n	%
Have you heard of PCDSI before?	Yes	37	69.8
	No	16	30.2
How did you hear about PCDSI?	Newsletter	10	17.8
	Family Forum	5	9.4

BEST COPY AVAILABLE

Table 1 continued **Questions**	**Responses**	n	%
(How did you hear about PCDSI?)	Deaf-Blind intervention project	2	3.8
	Another parent/family	3	5.7
	Other	17	32.1
	Not asked	16	30.2
Do you receive a newsletter form PCDSI?	Yes	7	13.2
	No	29	54.7
	Don't know	17	32.1
How useful is the Newsletter? Would you say it is . . . Only people who said they received the newsletter were asked this question. Due to interviewer error, one person who should have been asked was skipped.	Very useful	10	18.9
	Somewhat useful	11	20.8
	Only slightly useful	6	11.3
	Not useful at all	2	3.8
	Not asked	25	47.2
How effective is PCDSI in providing support for your family? Would you say it is . . .	Very effective	10	18.9
	Somewhat effective	11	20.8
	Only slightly effective	8	15.1
	Not effective at all	7	13.2
	Don't know	1	1.9
	Not asked	16	30.2
How helpful is PCDSI in supplying information for your family? Would you say it is . . .	Very helpful	12	22.6
	Somewhat helpful	14	26.4
	Only slightly helpful	2	3.8
	Not helpful at all	6	11.3
	Don't know	3	5.7
	Not asked	16	30.2
How interested are you in future involvement in a support group like PCDSI? Would you say you are . . .	Very interested	27	50.1
	Somewhat interested	17	32.1
	Not very interested	4	7.5
	Not interested at all	3	5.7
	Don't know	1	1.9
	Refused	1	1.9

References

Mar, H. (1992). Psychosocial services: Presentation. In J.W. Reiman and P.A. Johnson (Eds.), Proceedings of the National Symposium on Children and Youth Who are Deaf-Blind (pp. 97-111). Monmouth, OR: Teaching Research Publications.

Fredericks HD (1992): Review of the literature. In J.W. Reiman and P.A. Johnson (Eds.), Proceedings of the National Symposium on Children and Youth Who are Deaf-Blind (pp. 85-92). Monmouth, OR: Teaching Research Publications.

Leatherby J. (1993). Oral report to the Steering Committee of the Deaf-Blind Intervention Project.

Vadasy PF, Fewell RR (1986). Mothers of deaf-blind children. In R. Fewell and P. Vadasy (Eds.), Families of handicapped children: needs and supports across the life span (pp. 14-22). Austin, Texas: Pro-Ed.

DB-LINK

An Introduction to the International Organizations and Literature Related to Deafblindness

Betsy L. McGinnity
Perkins DB-LINK

To reflect the international nature of this article, the author uses the language "deafblind"(unhyphenated)—ED.

DB-LINK represents the first attempt in the United States to apply a methodical and organized effort to unify and disseminate the body of information related to deafblindness (see sidebar on terminology). The information specialists at DB-LINK have responded to more than 1800 requests for information since July 1993. To respond to these questions, staff make use of the DB-LINK Catalog database to identify pertinent literature and materials. While most of this literature was generated in the United States, DB-LINK also has access to literature from other countries. In responding to requests, it became apparent that within certain topic areas, the impact of the international literature is significant, (e.g., Usher Syndrome [Sense, United Kingdom], objects of reference [Sint Michelsgestel, Netherlands], or the intervener model [United Kingdom and Canada]).

The perspectives represented in the international literature are sometimes very different from those of the United States. Accessing these materials afford the reader the opportunity to evaluate how cultural values, government, geography, economy, and population demographics can affect theory and practice. As an example, the U.S. literature related to quality of life is often replete with language referring to independence and self-sufficiency, while the Nordic literature related to quality of life discusses combating isolation and developing methods to help people connect with each other. A review of the literature also demonstrates how much we have in common.

The purpose of this article is to serve as an introduction to the international, primarily European, sources of information related to deafblindness that are available in English.

The literature to which DB-LINK has access is frequently developed by one of the many agencies and organizations that are connected to individuals who are deafblind. Many of these organizations publish materials in English. Most countries are now using the term "deafblind." The use of the single word rather than the hyphenated term was adopted at the world conference of International Association for the Education of Deafblind People (IAEDB) in Ordoro, Sweden in 1991. It was felt that the single word more accurately represented the uniqueness and significance of "deafblindness" rather than the sum of deafness and blindness.

IAEDB was founded over 30 years ago to promote the education of deafblind children and young adults throughout the world. Membership includes representatives from 59 countries. IAEDB holds world conferences every four years and publishes their proceedings from these conferences in English. Recent world conferences were held in Poitiers, France in 1987 and in Orebro, Sweden in 1991. Topics addressed in the proceedings include quality of life, assessment, communication, Usher Syndrome, staff development and adventitious deafblindness. The 11th IAEDB World Conference, "Working and Growing Together," was held in July 1995 in Cordoba, Argentina.

The European Region of IAEDB also holds conferences within Europe. The most recent was held in Potsdam, Germany in 1993. The proceedings from this conference number over 500 pages and cover a wide array of topics, including "Cultural Differences in Early Intervention", "Access to Context—a Basic Need," and "Evaluation of the Social Relationships Between the Deafblind Person and Society."

IAEDB also publishes a newsletter, *Deafblind Education*, twice yearly. The newsletter's focus includes program description, and feature articles on subjects ranging from developing interpreter services in Europe to an examination of the neuropsychological aspects of communication and development. Articles are contributed by authors in both developing and developed countries.

Forty years ago a parent group was initiated in the United Kingdom by two young mothers, Peggy Freeman and Margaret Brock, whose correspondence began with their shared experience of raising babies who were deafblind as a result of maternal rubella. That parent group eventually became Sense, the National Deafblind and Rubella Association. Today, Sense has a staff of almost 1000, a main office in London, six regional centers throughout the U.K., three family centers, a family and respite center, and four special workshops and occupation centers. In addition to providing direct services to children and young adults who are deafblind and their families, Sense conducts staff training activities and sponsors conferences in the U.K. They also publish reports and proceedings from conferences and seminars held in the U.K. Sense publishes a quarterly magazine, *Talking Sense*. The magazine's regular format includes a news section focusing on government and commercial policy issues affecting people who are deafblind, program updates from throughout the U.K., feature articles on a wide array of topics, and membership news. Recent issues have featured articles about how a family adjusted to their son's diagnosis of Usher Syndrome, how to initiate mobility training with a

student who is totally deafblind, and a two-part series on intervention.

Sense's Usher Syndrome Services and the British Deaf Association collaboratively sponsor the Usher in the Deaf Community Project. The objective of the project is to promote Usher Syndrome education/awareness among members of the british deaf sign language-using community. The project has created a range of information leaflets that explain Usher Syndrome and were designed specifically for deaf people. The materials include many illustrations and short verbal descriptions. Sense will hold a conference in October 1995 to report on their four-year project and to share materials used in the development of their outreach programs.

The World Blind Union has a Standing Committee on the Activities of Deafblind People. This group includes a large proportion of people who are deafblind and has a particular focus on rehabilitation issues. Proceedings were published from the 5th Helen Keller World Conference held in Osimo, Italy in 1993. The conference theme was "The Quality of Life of Deafblind People, Realities and Opportunities." Among the major topics that were addressed was an overview of organizations of the deafblind, with specific descriptions of the models utilized in France, Denmark, and the United States. Another highlighted issue was the situation in developing countries, with a special focus on India, Africa, and South America.

The Nordic Staff Training Centre (NUD) in Dronninglund, Denmark conducts staff training courses for the Nordic countries (Denmark, Norway, Sweden, and Finland) related to all aspects of deafblindness. They make a variety of their publications available in English. Denmark also has an information center for acquired deafblindness and an information center for congenital deafblindness, each of which provides, similar to DB-LINK, comprehensive information services.

The Canadian Deafblind & Rubella Association also sponsors conferences and publishes proceedings. The next conference, "Living and Learning: A Lifelong Adventure," is scheduled for May 8–11, 1996 at the University of British Columbia in Vancouver, BC, Canada.

ONCE, the Spanish National Organization for the Blind, has translated a number of books related to deafblindness into Spanish. They maintain a database that identifies literature available in Spanish about blindness and deafblindness. They help to make these materials available throughout Latin America.

In this information age, technology is available that allows individuals to have immediate access to information from all over the world. A lot of energy is being expended on the part of information providers to organize and make available information related to deafblindness via the Internet. As DB-LINK continues to organize its resources, it creates even greater opportunities for sharing and exchanging ideas. This profession will be influenced by the ever-expanding influx of ideas from other cultures and other countries. Ultimately, this may lead to better educational services and outcomes for children who are deafblind.

DB-LINK can assist you in accessing any of the materials mentioned.

DB-LINK
345 N. Monmouth Ave.
Monmouth, OR 97361
voice: (800) 438-9376
TTY: (800) 854-7013
e-mail:leslieg@fsa.wosc.osshe.edu

Contact information for the organizations mentioned in this article

International Association for the Education of Deafblind People (IAEDB)

Individual membership is open to anyone and is without charge. An annual donation of $20 is requested. Each country can have a representative on the Executive Committee for every 10 individual members. There is a maximum of three representatives per country.

Corporate membership is open to any school, association, society or any similar organization. There is an annual subscription of $200. Each corporate member can have one representative on the Executive Committee.

All members will receive *Deafblind Education* and may vote at the World Conference.

IAEDB
c/o Sense
11-13 Clifton Terrace
Finsbury Park
London N4 3SR United Kingdom

Canadian Deafblind and Rubella Association
747 Second Ave East, Suite 4 Tel: (519) 372-1333
Owen Sound, ON N4K 2G9

Conference on Deafblindness
Canadian Deafblind and Rubella Association
BC Chapter
Box 140-5055 Joyce Street Tel/TTD: (604) 436-1882
Vancouver, BC V5R 4G7 Fax: (604) 430-3415

Nordic Staff Training Centre (NUD)
Slotsgade 8
DK-9330 Dronninglund

Organizacion Nacional de Ciegos Calle del Prado (ONCE)
C/ Quevedo, 1 Tel: 589 45 25-26
28014 Madrid Spain Fax: 589 45 27

Sense
11-13 Clifton Terrace Tel: 44 171 272 7774
Finsbury Park Fax: 44 171 272 6012
London N4 3SR
United Kingdom

World Blind Union
Committee on the Activities of Deafblind Persons
c/o Stig Ohlson, Chairperson
Association of the Swedish Deaf-Blind
S-122 88 Enskede, Sweden

SIDEBAR ON TERMINOLOGY

In 1991, Salvatore Lagati of the Servizio di Consulenza Pedagogica in Trento, Italy began a crusade to get international acceptance of the single word "deafblind" in place of the hyphenated word "deaf-blind." His belief was that "deafblindness is a condition presenting other difficulties than those caused by deafness and blindness"(Lagati,1993 p. 429). The hyphenated term indicates a condition that "sums up the difficulties of deafness and blindness." The single word would indicate a different, unique condition and that impact of dual losses is multiplicative rather than additive.

Lagati wrote and explained his proposal to 30 agencies throughout the world who work with people who are deafblind. He received very positive feedback from all of the people who responded. In Germany, Poland, Russia and the Nordic countries, the word "deafblind" has always been used without a hyphen. Representatives from other countries including the United States, France, Great Britain, India, Spain and Switzerland agreed that the change was desirable. Lagati presented this information at the IAEDB International Conference in Orebro, Sweden.

By 1993 both IAEDB and Sense had agreed to use the term "deafblind" in their publications. The Canadian Deafblind and Rubella Association also adopted the term. Lagati reported these results at the European Conference of IAEDB in Potsdam, Germany in 1993.

Salvatore Lagati wrote an article that appears in the most recent *Journal of Visual Impairment & Blindness, Special Issue on Deaf-Blindness*. He is now proposing that "the field should come to some agreement on the definition of the term" and then to "use the unhyphenated, one-word term in all publications." (Lagati, 1995, p.306).

This proposal faces an uncertain future in the United States. Terminology has been a hotly debated issue for some time in this country. Political correctness also seems to have greater influence in the US than in many other countries. Recent synonyms have included "dual sensory impaired," "auditorally and visually challenged," person "with deaf-blindness," etc. Editorial policy for *Deaf-Blind Perspectives* (Reiman, 1993) requires the use of the language "person who is deaf-blind." This usage seems to have general acceptance in the U.S. Perhaps, if Salvatore Lagati keeps up his crusade, "person who is deafblind" will have global acceptance in the future.

To contact Salvatore Lagati:
Salvatore Lagati, Ph.D.
Director
Servizio di Consulenza Pedagogica
P.O. Box 601
38100 Trento, Italy

16

References

Lagati, S. (1993). Deafblind (Sourdaveugle-Taubblind-Sordociego): A correct name and a clear definition. Proceedings Access to Cultur, III European Conference of the International Association of Deafblind People Equal and Exceptional. Potsdam, Germany: Oberlinhaus

Lagati, S. (1995). "Deaf-Blind" or "Deafblind"? International perspectives on terminology. Journal of Visual Impairment and Blindness, Special Issue on Deaf-Blindness, 89 (3) 306.

Reiman, J. (1993) Rationale for editorial policy on terminology. Deaf-Blind Perspectives, 1 (1), 2–4.

Additional Readings

5th Helen Keller World Conference, the Quality of deafblind people:realities and opportunities, Osimo, Italy September 25-30, 1993 / World Blind Union's Standing Committee on the Activities of Deaf-Blind People. 1993.

III. European Conference of the International Association for the Education of Deafblind People Equal and Exceptional. Potsdam (Germany) 31 July - 5 August 1993. Proceedings / International Association of the Education of Deafblind People. Potsdam, Germany: Oberlinhaus, 1993.

Second European conference, report 22-27, October 1988, England / European Commission on Activities for the Deaf-Blind. Peterborough, England: National Deaf-Blind League, 1989.

Summerscale, J. & Boothroyd, E. (1994) Proceedings of the U.K. Conference, Deafblind education: developing and sustaining appropriate provision, Birmingham, England.

Deafblind Education, The Journal of the International association for the education of Deafblind People.

Talking Sense, The Magazine of Sense, the National Deafblind and Rubella Association.

◆◆◆◆◆◆◆◆

We encourage you to copy and share information from *Deaf-Blind Perspectives*, but please provide appropriate citations.

Personnel Preparation Past, Present and Future Perspectives

Barbara A. B. McLetchie
Boston College

The author acknowledges the contributions of Stephanie MacFarland and Marianne Riggio. For a complete listing of personnel preparation programs in deaf-blind education, contact DB-LINK.

The 1992 National Symposium on Children and Youth Who Are Deaf-Blind, sponsored by the Office of Special Education and Rehabilitation Services (OSERS) had as "a single goal—a brighter future for children and youth who are deaf-blind" (Reiman, 1993, opening remarks). The National Symposium culminated with several recommendations that would improve services to people who are deaf-blind throughout the country (Reiman & Johnson, 1993).

This article validates the need for continued and increased federal involvement in the preparation of teachers to educate students who are deaf-blind. Further, it discusses the progress made in three of the National Symposium recommendations related to teacher preparation in the field of deaf-blindness: a) the need for additional teachers, b) the need to develop teacher competencies unique to teaching learners who are deaf-blind, and c) the need for collaboration among university personnel, families, service providers and adults who are deaf-blind.

Federal Involvement

The issue of continued federal support in the field of deaf-blindness, including teacher preparation, may seem pale in comparison to the overall radical reductions and eradication of fiscal support the present Congress already has executed or proposes in numerous areas of human services. However, the need for continued federal commitment—with creative collaboration among service providers, families, and adults who are deaf-blind—is more crucial than ever in maintaining and providing basic and adequate educational services in this field.

Historical events over the last three decades clearly demonstrate the impact the federal government has had on teacher preparation in the field of deaf-blindness. In the 1960s, the Rubella epidemic created a national medical emergency that left more than 5000 children with combined vision and hearing losses and unique, complex educational needs. The needs of these children could not be met in traditional special education programs. To assist meeting the needs of this extremely low incidence population the federal government established several high quality university personnel preparation programs in deaf-blindness in the late 1960s and 1970s. Large numbers of aspiring teachers and others who were uncertain of their future studies were encouraged to choose careers in deaf-blind education because of the availability of federal grants in this field. Additionally, the federal government funded 10 Deaf-Blind Regional Centers across the country. In the 1970s, the vast majority of learners who were deaf-blind were being educated in special schools. These schools developed strong collaborative links with the Deaf-Blind Regional Centers and university personnel preparation programs. This infusion of federal support, along with an increase in trained personnel, fostered new and innovative programs to assist children who were deaf-blind and their families: new assessment tools and curricula were developed, communication modes were adapted for learners who were deaf-blind and had other disabilities, and many parents became actively involved in educational interventions. The activities in the 1960s and 1970s allowed graduates of personnel preparation programs to feel confident about finding a job in the field of deaf-blindness.

In the 1980s, the federal government reorganized the funding structure within the Department of Education. This decreased federal involvement meant that fewer teacher preparation programs continued to receive funding. Consequently the number of personnel preparation programs in the area of deaf-blindness were reduced to a handful despite the fact that there continued to be a steady increase in the numbers of learners who were deaf-blind. The most recent census reports 9,783 infants, children, and youth who are deaf-blind (Baldwin, 1994)—twice the number reported after the Rubella epidemic.

Currently, nearly 80% of learners who are deaf-blind are being educated in local schools (Heumann, 1994-95). Moreover, the population is more widely dispersed than ever before, a trend that is likely to continue with the national move to educate learners who are disabled in their neighborhood schools (Collins, 1992). With this dispersion of the population graduates of personnel preparation programs in deaf-blindness find it increasingly difficult to find positions in the field of deaf-blindness. Typically, school districts with only one learner who is deaf-blind are not willing to pay for a teacher trained in deaf-blindness even though the child has unique educational needs that may not be met by a generic special education teacher.

In 1995, the supply of qualified teachers is "critically limited" (Heumann, 1994-95). As of the summer of 1995 there are only five university programs that are federally funded through the Division of Personnel Preparation, Low Incidence Disabilities. And states have not been able to meet the needs of personnel development in deaf-blindness through their Comprehensive System of Personnel Development (CSPD). Because the number of students who are deaf-blind in each state is extremely small in comparison to the number of students with other disabili-

ties, the concern is that students who are deaf-blind are considered a low priority when providing appropriate services at state and local levels.

The unique needs of the relatively few students who are deaf-blind, dispersed in classrooms across the country, justify federal support. Without federal involvement the highly specialized services required to educate children who are deaf-blind are at high risk of becoming fragmented or nonexistent. The low priority that states assigned to personnel development in the deaf-blind field may soon become a more critical issue with the impending move by Congress to provide block grants to states that minimize federal involvement. In essence, events of the past and present show that even with federal support there are still too few teachers of students who are deaf-blind. To remove or reduce this support would be unconscionable.

Additional Teachers

Results of a national survey of state and multistate coordinators under Section 307.11 completed for the National Symposium in 1992, and a follow-up survey two years later, support Assistant Secretary Heumann's assertion that a severe shortage of qualified personnel exists in the field of deaf-blindness. In 1992, a national survey from 47 state and multistate coordinators revealed that only 6% or 224 of the 3668 teachers working with 6741 learners who were deaf-blind were trained in deaf-blind education at the university level (McLetchie, 1992). Results of a 1994 follow-up survey of 48 coordinators indicated only an estimated 6% or 347 of the 5445 teachers serving 9046 infants, children, and youth have had specific teacher preparation in deaf-blind education (McLetchie & MacFarland, 1995).

A major recommendation by the National Symposium, relating to personnel preparation, was the need for more teachers. This recommendation included the need for providing federal support to at least 10 university programs specializing in training teachers in deaf-blindness. Though some progress has been made in this area, it remains woefully short of the need. In 1992, four personnel preparation programs in deaf-blind teacher education were funded under OSERS, Division of Personnel Preparation. One other teacher education program was funded through a federal grant to a state. These programs along with three others funded through the Hilton/Perkins Program graduated a total of 18 teachers. Currently, five programs are funded under the Division of Personnel Preparation, Low Incidence Disabilities: one federal grant to a state, one program that receives no external funds, and three other programs partially funded through the Hilton/Perkins Program. Hilton/Perkins contributes to three of the programs that are federally funded and partially funds three other programs. These programs graduated 36 teachers in 1994. This two-fold increase in preparing more qualified personnel over 1992 levels demonstrates significant progress in preparing more qualified personnel. However, the current picture is uncertain.

Given the present funding trends, it is highly questionable if the federally funded programs will survive beyond their present grant periods. And though The Hilton/Perkins Program has provided start-up support to some of these programs, it cannot support these programs to the extent necessary to meet the current needs. Maybe most disconcerting is that no specific Requests for Proposals to prepare teachers in deaf-blind education have been issued by OSERS, Division of Personnel Preparation since the National Symposium.

Teacher Competencies

Another major National Symposium recommendation related to personnel preparation was the need to establish national competencies in the deaf-blind teaching profession (McLetchie, 1992; Davidson, 1992). Competencies relate to the knowledge and skills teachers require to educate learners who are deaf-blind. For example, teachers need knowledge of the wide variety of communication modes used by learners who are deaf-blind (objects, tactile symbols, pictures, English and other visual/tactile sign systems, fingerspelling, large print or braille, etc.). Teachers need skills in using a variety of communication modes in order to adapt to each learner's preferred mode(s) of communication. Teacher competencies can help assure that students who are deaf-blind not only have access to education but that their education meets a prescribed level of quality. Competencies incorporated into personnel preparation courses and field experiences at the university level can provide a standard for certifying university programs or evaluating grant proposals. National competencies also can elevate teaching in the deaf-blind field to a higher level of professionalism and be a positive force for professional identity. Strong competencies can also serve as self-evaluation tools for teachers so they can be ongoing learners who pursue additional training opportunities to increase their knowledge and skills. In addition, the competencies will assist school administrators in making judgments regarding a teacher's current knowledge and skills and his or her future training needs.

Collaboration

In 1993, The Perkins National Deaf-Blind Training Project was funded by OSERS, Services for Children with Deaf-Blindness Program. The project provides a mechanism for national collaboration with a central focus upon teacher preparation. (The project's goals relate to the National Symposium recommendations discussed in this article: the need to train more teachers and the need to develop teacher competencies unique to deaf-blindness). Collaboration within this project occurs at many levels fostered by the project steering committee, which includes representation from

- *Parent/family organizations*
  National Family Association for Deaf-Blind (NFADB)
- *Adult and transition services*
  Helen Keller National Center Technical Assistance Center (HKNC-TAC)
- *Deaf-blind consumer organizations*
  American Association of the Deaf-Blind (AADB)
- *state and multistate coordinators of Section 307.11 programs*
  Teaching Research Assistance to Children Experiencing Sensory Impairments (TRACES)
- OSERS
- The National Information Clearinghouse On Children Who Are Deaf-Blind (DB-LINK)
- University personnel preparation programs
- National Coalition on Deaf-Blindness.

The project collaborates with universities that have existing programs or faculty with expertise in deaf-blindness. The regions, university sites and faculty are:

- *Northeast Region*, Boston College (Dr. Barbara McLetchie) and Hunter College (Dr. Rosanne Silberman)
- *Southeast Region*, Florida State University (Dr. Pearl Tait)
- *North Central Region*, (Dr. Lou Alonso and Susan Bruce Marks)
- *South Central Region*, Texas Tech University (Dr. Roseanna Davidson)
- *Southwest Region*, San Diego State University (Dr. Kathee Christensen)
- *Northwest Region*, University of Washington (Dr. Norris Haring)

During the 3-year grant period (October 1993 - October 1996) the project provides two consecutive graduate level summer institutes in each of the six regional university sites. The grant provides funds for travel, tuition, room and board for two participants from each state and territory. The two selected topic areas, based upon results of national survey data from 307.11 Coordinators, practitioners, and families are: Strategies to Assist Learners Who are Deaf-Blind in Developing Communication Competence and, Strategies for Including Learners Who are Deaf-Blind in Regular Schools and Communities. Prior to each regional summer training institute, the university site coordinator for the region, 307.11 coordinators, representatives from TRACES, HKNC-TAC, and grant staff participate in regional planning team meetings. Meetings focus on the selection of course content area (communication or inclusion), presenters, and logistics for the institutes. The 307.11 coordinators select participants to ensure that training meets the needs of each state. The 307.11 program, TRACES, and HKNC-TAC have collaborated with the project and have contributed valuable time and resources. These efforts include attending regional planning team meetings, funding additional participants to attend summer institutes, and contributing the time of their project staff to present at summer institutes.

Eight summer institutes were held in 1994 and 1995 and approximately 200 people enrolled. In 1994, the summer institutes on communication were held in the Northeast Region through Hunter College at the Helen Keller National Center, Sands Point, New York and in the South Central Region through Texas Tech University at its site in Junction, Texas. Approximately 50 people participated. In the summer of 1995, institutes on inclusion and communication were offered through Hunter College and Texas Tech University. Institutes on communication were held at the other four university sites—Michigan State University, San Diego State University, Florida State University, and University of Washington. Next summer, these four universities will provide training on including learners who are deaf-blind in their home schools and communities. The institutes are targeted to train teachers. However, parents, occupational and speech language therapists, vision specialists, interveners, and 307.11 state coordinators have participated.

Progress in developing competencies has occurred over the last two years. The Perkins National Deaf-Blind Training Project has begun to develop competencies in the deaf-blind teaching profession. A competency subcommittee of the National Consortium has developed a draft of the competencies that will be shared with the entire consortium for input in the early fall of 1995. By March of 1996, the competencies will be field tested nationally. The finalized competencies will be disseminated in September 1996, at the close of the grant period.

Progress in collaboration, in training more personnel, and in developing competencies unique to teaching learners who are deaf-blind has occurred since the 1992 National Symposium. Future progress in teacher preparation in the deaf-blind field is tenuous given the present political shift away from federal involvement. Therefore, collaboration among university personnel, service providers, families, and adults who are deaf-blind must continue and expand with creativity and energy—even more so if current federal grants expire. In the larger picture, the deaf-blind field must unite and advocate for quality educational opportunities. Education is a powerful tool that enhances the quality of lives of all people in our society and provides a "brighter future for children and youth who are deaf-blind," (Reiman, 1992, Opening remarks).

Continued on next page

Continued from previous page

References

Baldwin, V. (1994) A dangerous misrepresentation of the facts: The 15th annual report to congress on the implementation of the individuals with disabilities act. Deaf-Blind Perspectives, 1,(3), 1-3.

Collins, M. (1992). Reflections and future directions. Proceedings of the national conference on deaf-blindness: Deaf-blind services in the 90's. Reno, Nevada: Hilton/Perkins National Program, Conrad N. Hilton Foundation.

Davidson, R. (1992). Personnel preparation: Reaction. In Reiman, J. W. & Johnson, P. A. (Eds.) Proceedings of the national symposium on children and youth who are deaf-blind (pp. 159-163). Monmouth, Oregon: Teaching Research Publications.

Heumann, J. (1994-95). Improving outcomes and the quality of life for children, youth, and adults who are deaf-blind. Deaf-Blind Perspectives, 2, 1-3.

McLetchie, B. and MacFarland, S. (1995). The need for qualified teachers for students who are deaf-blind. Journal of Visual Impairment and Blindness, 89, 244-248.

McLetchie, B. (1992). Personnel preparation: Presentation. In Reiman, J. & Johnson, P. (Eds.) Proceedings of the national symposium on children and youth who are deaf-blind (pp. 145-158). Monmouth, Oregon: Teaching Research Publications.

Reiman, J. & Johnson, P. Eds. (1992). Proceedings of the national symposium on children and youth who are deaf-blind. Monmouth, Oregon: Teaching Research Publications.

Reiman, J. (1992) Opening remarks. Proceedings of the national symposium on children and youth who are deaf-blind. Monmouth, Oregon: Teaching Research Publications.

❖❖❖❖❖❖❖❖

New Local Deaf-blind Association Established

The Pennsylvania Society for the Advancement of the Deaf, Inc., Greater Harrisburg Chapter, is announcing the formation of the Central Pennsylvania Association for the Deaf-Blind (CPDAB)

CPDAB is in the developmental stages and interested parties should contact

Zenola and James Tyson
125 North Harrisburg Street
Steelton, PA 17133
TDD:(717) 986-0773

Interpreter-Tutor

The **Interpreter-Tutor** is the second in the five-part ***You & Me*** series illustrating the education of a child who is deaf-blind, in the neighborhood school. This video focuses on the duties of the interpreter-tutor, the job qualifications, and the supports necessary for the success of this position in the educational setting. The video will be available from Teaching Research Publications in December, 1995.
Cost: $15.00

To order, contact

Teaching Research Publications
345 N. Monmouth Ave.
Monmouth, OR 97361
Phone:(503) 838-8792
Fax:(503) 838-8150

20

Hand in Hand Materials now Available from American Foundation for the Blind

Huebner, K., Prickett, J., & Rafalowski-Welch, T. (1995). Hand in Hand: Essentials of communication and orientation and mobility for your students who are deaf-blind. New York: AFB Press.

This two-volume self-study text—with contributions form more than 30 nationally recognized experts in issues relating to persons who are deaf-blind—explains how students who are deaf-blind learn, and focuses on essential communication.
Cost: $60.00 + s/h

Huebner, K., Prickett, J., Rafalowski-Welch, T., & Jofee, E., Eds. (1995). Hand in Hand: It can be done. New York: AFB Press.

This one-hour video is an introduction to working with students who are deaf-blind. Accompanied by a discussion guide, the video can be used in its entirety or in sections, and is designed for use with parents, regular educators, and community members.
Cost: $49.95 + s/h

Huebner, K., Prickett, J., Rafalowski-Welch, T., & Jofee, E., Eds. (1995). Hand in Hand: Selected reprints and annotated bibliography on working with students who are deaf-blind. New York: AFB Press.

This collection of 27 journal articles on the topics of communication, orientation and mobility, functional skills, implications of various etiologies, and instructional strategies and intervention issues is accompanied by a description of more then 160 important print and audiovisual resources and information on how to obtain them. Cost: $ 29.95 + s/h

Prickett, J., Jofee, E., J., Rafalowski-Welch, T., & Huebner, K. (1995). Essentials of communication and orientation and mobility for your students who are deaf-blind—A trainer's manual. New York: AFB Press.

This inservice training guide gives structured information and guidelines for using the self-study materials with various audiences. Focusing on the needs of the trainer, it provides sample blueprints for workshops, as well as an overview of training, assessment, and evaluation. Cost: $29.95 + s/h

For more information, contact

AFB Press
11 Penn Plaza, Ste 300
New York, NY 10001
(212) 502-7652

Calendar of Events

April 15, - May 26, 1996, Birmingham, United Kingdom
Professional Development Programme. This professional development program offers participants the opportunity to increase knowledge and skills in a specialist area relating to sensory impairment, visit and observe different specialist services throughout the U.K., discuss work and plans with professionals experienced in similar work, and produce a project related to their work at home with the support of specialists in the U.K.

Contact:

Professional Development Programme
Sense International
The Princess Royal Centre
4 Church Road
Edgbaston
Birmingham B15 3TD United Kingdom

June 19–23, 1996, Toronto, Canada
Reaching Out, the Canadian Conference of Deaf-Blind People. Conference program to be announced.

Contact:

Reaching Out Conference Committee
201-44 Stubbs Dr.
Willowdale, Ontario M2L 2R3 Canada

Ph (416) 225-4482
Fax: (416) 510-8071
E-mail: jascal@hookup.net

21

Deaf-Blind Perspectives

- ❑ I enjoyed this issue of *Deaf-Blind Perspectives* but I am not on your mailing list. Please send future issues to the address below.
- ❑ I've moved! Please send future issues of *Deaf-Blind Perspectives* to my current address.
- ❑ I'm buried in interesting publications! Please remove my name from your mailing list.

Name: _____ Agency: _____

Street: _____ City: _____ State: ___ Zip: _____

Comments _____

_____

_____

Mark appropriate categories (3 max.)

- ❑ Person or parent of person who is disabled
- ❑ Special education (*e.g.*, teacher, aide)
- ❑ Administration (*e.g.*, Dept. of Ed., project director)
- ❑ Service provider (*e.g.*, social worker, group home)
- ❑ Technical assistance provider
- ❑ Higher education teacher/researcher
- ❑ Regular education (non Spec.-Ed.)
- ❑ Therapist (*e.g.*, OT/PT/speech)
- ❑ Teacher trainer
- ❑ Government personnel
- ❑ Medical professional
- ❑ Other _____

Please send my copy in:

- ❑ Grade 2 braille
- ❑ Large print
- ❑ Standard print
- ❑ ASCII

Mail to: *Deaf-Blind Perspectives* • Teaching Research Division • 345 N. Monmouth Ave. • Monmouth, OR 97361 • or call Randy Klumph (503) 838-8885, TTY (503) 838-8821, fax: (503) 838-8150, E-mail: klumphr@fstr.wosc.osshe.edu

Deaf-Blind Perspectives can be downloaded from Library 5 of the CompuServe Disabilities Forum. 0995

Deaf-Blind Perspectives is a free publication, published three times a year by the Teaching Research Division of Western Oregon State College. The positions expressed in this newsletter are those of the author(s) and do not necessarily reflect the position of the Teaching Research Division or the U.S. Department of Education.

Deaf-Blind Perspectives
Teaching Research Division
Western Oregon State College
345 N. Monmouth Ave.
Monmouth, OR 97361

Non-Profit Organization
U.S. Postage
PAID
Permit No. 344
Salem, OR

Forwarding & Return Postage Guaranteed,
Address Correction Requested

Deaf-Blind Perspectives

Volume 3, Issue 2 Winter 1995/1996

Simulation Exercises to Help Stimulate Discussions about Communication Strategies Used with Students who are Deaf-Blind and Developmentally Delayed

Jennifer White
Puget Sound Educational Service District

Lyle T. Romer
University of Washington

Deaf-Blind Perspectives has invited another author to respond to, and expand on this topic as it applies to students who are deaf-blind without cognitive challenges. —ED.

Communication is necessary to interact meaningfully with others. Often it is the block between students who are deaf-blind and developmentally delayed and their peers in schools. Information about various strategies can facilitate curiosity and exploration of ways to overcome these blocks. Most students in public and private schools are lacking role models of meaningful interactions between people using different communication strategies. People with developmental delays who lack a language base and use alternative strategies foreign to most outsiders are often seen as severely delayed. This, coupled with the dual sensory impairments of deaf-blindness and the lack of information about these losses, leaves huge gaps in our knowledge about how to communicate with these students. Open discussions about these issues and exploration of communication strategies can help identify solutions.

The following four simulation activities are used to introduce alternative communication strategies to general education students: (a) Toy Sculpture Descriptions (Cokely & Baker, 1980); (b) Blindfolded Art Projects; (c) Introduction to Sighted Guide; and (d) Non-language Sentences (Kettrick, 1988). Before proceeding with any activities you should clarify the students' options to participate, and provide some cautions about simulation activities. First, any student can choose not to join the activity. For non participants the only requirement is to observe and stay unobtrusive to those participating. Also, when the activity recommends a blindfold, students can choose to close their eyes if the blindfold is uncomfortable.

Second, caution students about pity. Often simulation experiences are equated with a disability. These exercises will not result in "knowing" what it's like to be deaf-blind or cognitively impaired. There is no way for anyone to experience that through simulation. When we put on a blindfold we experience an immediate loss of a sense we are used to having. Since there is no acclimation time, our perception of the experience will differ from that of a person who has had time to adapt. A typical reaction to this immediate loss is the feeling that you would never be able to adjust. Students sometimes say, "I would kill myself if I had to live like this," or, "Oh, life must be so hard for blind people." It is good to discuss this before beginning the activities. Students should learn that pity is a common reaction. They should also know that it is a reaction that is superficial. Students should remember that they cannot experience firsthand what blindness is like. Since many of them have no role models in their lives from whom they have learned about blindness, their knowledge of blindness is abstract. Students need to learn that people with visual impairments can lead full and normal lives. Meeting people who are blind, or deaf-blind can offer more realistic perspectives to students.

In This Issue

Simulation Exercises to Help Stimulate Discussions about Communication Strategies Used with Students who are Deaf-Blind and Developmentally Delayed 1
Jennifer White & Lyle T. Romer

From The Editor 6
John Reiman

A Special Thanks 7
Vic Baldwin

***Hand in Hand* Publications from the AFB Deaf-Blind Project** 7

DB-LINK Fact Sheets 8

"Free To Be Me" 9
Joann Twitchell

Announcements/Calendar of Events 10

For Your Library 11

Toy Sculpture Descriptions

Objectives

- To sense the need for, and to utilize space in visual communication strategies by exploring the ideas of referencing[1] and communicator's perspective[2].
- To begin to understand the differences between linear sequential communication, such as in English, where meaning relies heavily on word order, and inflective communication, such as in American Sign Language (ASL), Russian, or Latin, where affixes are often attached to words to show how symbols are related regardless of where they are placed in the sentence.
- To experience the process of agreeing on certain symbols and rules of communication without using language.

Materials

- Bags of toys, each containing two identical sets of five toys, for example, two horses, two fences, two dice, two airplanes, two snakes.
- Dividers to place between partners. These prevent partners from seeing each other's toys. Manila folders or textbooks can be used.

Description

Tell students to form pairs. Give each pair one bag of toys to divide between them so that each person will have the same toys as his or her partner. A divider is placed between the pair before beginning. This exercise is nonverbal: No vocalizations are allowed; in fact no language is allowed, signed or spoken. (Deaf and hearing students alike are instructed to use no language.) Instead, students are instructed to use their bodies, faces, gestures, and space to communicate with their partners. The object of the exercise is for one person to arrange the toys in some order or configuration and then to describe to the partner how to set his or her toys up to look the same. Demonstrate with a volunteer and answer questions before asking students to begin.

It is very challenging for students to refrain from using their natural language during this exercise. Circling the room to remind them to think of another way to communicate is a good idea. For example, hearing students will often decide who goes first by talking about it. When asked, they can come up with several alternative ways to establish this: pointing to themselves and then holding one finger up to signify first, holding out both hands to the other person offering them the chance to begin, or pointing alternately to themselves and their partner and shrugging their shoulders while raising their eyebrows to ask who should begin.

[1] In ASL, referencing refers to setting nonpresent objects, places, and people in space. Once established, the signer can refer to these objects and people without identifying them by formal name each time. Also, referencing means the process of referring to familiar and established communication. For example, once a symbol for a toy is set in space, it can be used to show the relationship of subsequent toys.

[2] Communicator's perspective is the idea that all people in the communication are seeing space from the perspective of the communicator.

Deaf-Blind Perspectives
Volume 3, Issue 2
Winter 1995–96

❖❖❖❖❖❖❖❖

Executive Editor
John Reiman
Teaching Research

Managing Editor
Bruce Bull
Teaching Research

Consulting Editors
Harry Anderson, Florida School for the Deaf and Blind; Bruce A. Dalke, Teaching Research; June Downing, California State University – Northridge; Joyce Ford, Parent; Bud Fredericks, Editor Emeritus; Jay Gense, Mid Oregon Regional Program; Karen Goehl, Indiana Deaf-Blind Project; Barbara A. B. McLetchie, Boston College; Kathy McNulty, Helen Keller National Center; Robert Moore, Parent; Marianne Riggio, Perkins School for the Blind; Art Roehrig, Gallaudet University; Rosanne Silberman, Hunter College.

Production Editor
Randy Klumph
Teaching Research

❖❖❖❖❖❖❖❖

Deaf-Blind Perspectives considers all unsolicited manuscripts and employs an anonymous review process. Manuscripts should adhere to *American Psychological Association* standards. *Send both a printed copy and a disk copy (preferably DOS format) to:*

Deaf-Blind Perspectives
Teaching Research Division
345 N. Monmouth Ave.
Monmouth, OR 97361
(503) 838-8403
TTY (503) 838-8821
fax (503) 838-8150

BEST COPY AVAILABLE

Once the exercise has begun, students are to continue taking turns back and forth. Some pairs will have success from the beginning. Others will never get a completely replicated sculpture. Some pairs will increase their accuracy with each turn; others will not.

After the exercise is completed, ask the students to describe their experiences. The discussion that follows varies with each group and results in many insights about interpersonal communication skills, visual versus spoken language, the power of language skills and the frustration of losing them.

Many students have commented on the excitement of successes. When communication is smooth and they are working in a new medium, they feel thrilled to be able to get their points across. But when misunderstandings occur, or accuracy is not complete, many students resort to blaming the other person. One student put it best when quoting from an episode of the television show, M*A*S*H in which the character BJ comments on Americans, saying, "We assume that everyone will understand English if only we speak loudly and slowly enough." It seems easy to blame the other person when we feel very clear about our own communication skills and points we are making. Discussions regarding communication as a two-way interaction usually ensue here.

Students have brought up the question of whose responsibility it is when someone doesn't understand. If another person has let us know they are confused, and we continue with the same tactic of expression, where does the responsibility lie?

Blindfolded Art Projects

Objectives

- To explore the differences between helping and deciding for someone else.
- To explore dependency upon another as well as another's dependency on you.
- To begin to understand tactile methods of communication.

Materials

- Art supplies; paper, colored markers, glue, glitter, scissors, yarn, scrap cloth, and stencils.
- Blindfolds.
- Instructions written in bold print on a large piece of paper (large enough for all to see from their seats): "Help your partner make something, anything."

Description

Have students form into pairs. One person will be blindfolded. Explain that they will be blindfolded before they get any instructions. Only the sighted people in the room will know what the instructions are. This will be a silent exercise. No talking or vocalizations will be allowed. No tactile signing is allowed. The students will communicate using gestures, objects, and physical prompts.

After one person puts the blindfold on, hold up the instructions for all without blindfolds to see and say, "These are the instructions and here are the materials." Point out the materials.

Once students have completed a picture, sculpture, or other project, let them take the blindfolds off. Allow students time to talk with their partners first and then to talk as a group about this experience.

Ask the following questions to lead the discussion:

1. Did you understand what was expected of you?
2. Did you know what materials you could choose from?
3. Did you make what you wanted to make or did your partner decide for you?
4. How did your partner communicate to you?
5. If you could tell your partner one thing that was helpful and one thing that was not helpful, what would it be?

Explain to the group that this exercise was a set-up. They don't all have the skills to comfortably provide tactile information. The point is to think about why we take over for people when we don't know how to offer choices. Then discuss some successful strategies students used and offer some information regarding tactile methods of communicating: (a) letting the person know all the materials available by putting each one in his or her hand to explore; (b) letting the person set the materials down on his or her own desk or guiding them to do this and leaving materials where they are (you can't see where they've gone to when you are blindfolded); (c) making something yourself with the materials with the blindfolded person's hand placed on top of yours for them to "watch" tactually what you are doing and then offering them the materials. Those methods help orient the blindfolded person to the task and the choices available.

Introduction To Sighted Guide

Objectives

- To learn some techniques for safely guiding a person with a visual impairment.
- To experience the trust it takes to put your physical safety into someone else's hands.

Materials

-

Description

Depending on the school layout and weather, choose from two different exercises in sighted guide. For both give the following rules:

1. Vision and hearing are distance sensors. They supply us with information on how to react to our environment. For this exercise you will be blindfolded and will not have access to the same information you are used to getting about your environment. Because of this no horseplay is allowed. It's very tempting when your friend is wearing a blindfold to try to tease and taunt him. Don't. It is disrespectful in the deaf-blind community to surprise someone in this way.
2. There will be no talking or vocalizations allowed in this exercise. No tactile sign language or language of any kind can be used. Students must rely on tactile feedback with their partners.

Demonstrate with a volunteer the following techniques:

1. Guide the volunteer's left hand to your right elbow. The hand should be cupped around your elbow with the thumb on the outside of your arm. It should be a comfortable grip, yet one not easily broken.
2. Show that when guiding someone you become a safety block for their body. This means you must remember that you are now twice as wide as you normally are. It is your job to protect the person from objects blocking the path (open doorways, tables, shelves, tree branches). You can show this by walking through an aisle between desks, first alone and then guiding someone.
3. Always pause when there is a change in the terrain. You can show this by moving from a carpeted area to an area of tile, or something similar.
4. Doors and stairways can be very dangerous. Always take them slowly. Pause before entering or going up or down. When possible, gently guide the blindfolded person's hand to the railing of the stairway, or to the door being opened, to give him or her as much information as possible about the route.
5. Pay attention to signals from the person you are guiding. If he or she is pulling back on your arm it probably means you need to slow down. The object of the exercise is for your partner to trust that you will guide in a safe manner.

After demonstrating these techniques and answering any questions, begin the exercise. One person in each pair puts on a blindfold without getting instructions. After all the blindfolds are in place, hold up a sign with one of two directions. One option is to walk outside and pick up a small rock with the partner and return to the room. Another is to guide the partner to the water fountain and get a drink. The rock experience evokes some good discussion because it's hard to make sense of any meaning and the blindfolded person gets lost in wondering why they are doing this, similar to some students with cognitive and sensory impairments. These instructions can be varied to fit the needs of group size, age, and energy level. Generally, when the students are younger give very specific instructions such as "Go to the closet and help your partner get their coat on," or "Walk to the playground and meet me at the slide." With older students you may give more open-ended instructions: "Go outside with your partner and let him or her explore the environment, trees, and buildings."

When the exercise is completed, allow students time to talk with the partners and then talk as a group. Discuss the dependency involved in sighted guide and what it means to trust someone and be trustworthy as a guide. Also talk about how information was passed between partners. Students' comments have addressed the fear of not trusting their partner, wondering why everyone else was laughing at them, noticing the heightening of their other senses, how long it took to orient themselves, anger at the sighted partner for not providing enough information, delight at trying out a different way to take in the world, and the awkwardness of trying to make their communication clear to someone tactually. Discussing the lives of some deaf-blind people we know, or inviting a deaf-blind adult to speak with the class to answer questions about how to maneuver in the world without vision and hearing are excellent ideas.

Non-language Sentences

Objectives

- To experience the task of receiving and expressing abstract thought without the medium of language.
- To rely on gestures, props, and mime as the primary modes of communication.
- To begin to track one's own limits and levels of frustration when message clarity takes more effort to achieve.
- To begin to understand the notion that concepts do not equal words.

Materials

- Paper and markers.
- Box of toy props including food items, people, vehicles, animals, atlas, and a map of the United States
- Sets of questions found below. Have enough sets of questions so each pair of students gets a complete set. Each set consists of four slips of paper, each with one of the following sets of questions. One partner of each pair gets slips 1 and 3, the other gets slips 2 and 4.

First Slip:

1. How do you get to school in the morning?
2. What is your favorite kind of pizza?
3. Where would your ideal vacation be?

4. Is your house one or two stories?
5. What is your favorite T.V. show?

Second Slip:

1. Have you ever been to Paradise Lodge on Mt. Rainier?
2. What do you think is humankind's worst problem?
3. What kind of car do you drive?
4. Do you know how to sew?
5. Do you know how to change a tire?

Third Slip

1. What is your favorite sport?
2. Where did you go on your last vacation?
3. Do you have a garden?
4. Where was your father born?
5. Are you taller than either of your parents?

Fourth Slip

1. Where do you live now?
2. Where did you live five years ago?
3. What is your favorite ethnic food? (Chinese, Thai, Italian)
4. Do you have any pets? If yes, what are they?
5. What is your favorite holiday?

Description

Write the following directions on the board and read them to your students:

Find out from your partner the answers to the following questions. Do not use any language. You may draw, use props, natural gestures, and mime. Explain the word "language" to mean all agreed-upon symbols. Nothing from the typewriter keyboard can be used, and no symbols for woman or man. Arrows and pictures are the only symbols allowed when drawing.

Demonstrate with a volunteer using the question "What is your favorite color?" Point to yourself and then line the markers up on the table (standing them upright so all the class can see them). Begin with the first marker in line, pick it up and raise both hands in a thumbs-up sign. Kiss the marker and hold it high. Proceed to the second marker and give it a look of approval as well as a thumbs-up. The third marker gets a so-so hand movement (hand palm face down, open five fingers, rotate right downward movement and left downward moment from the wrist). To the fourth marker give a look of "could care less" by shrugging your shoulders and using facial expressions. Pick up the fifth marker and throw it on the floor with a distasteful look on your face. Then gather all the markers together and hand them to your partner with a shrug of your shoulders and raised eyebrows while pointing to them.

Remind the class of the instructions and add no talking to the list. Ask them how you got your partner to answer your question. They usually respond by noting that first you showed them your own favorite color then you asked for theirs. Then proceed with the exercise. Each partner takes turns asking the questions from his or her slips.

After completing as many questions as they can, allow students to talk with their partners followed by a group discussion. The group discussion involves topics such as how your life experience affects your answers. For example in the question, "Have you ever been to Paradise Lodge on Mt. Rainier?," some people who had never known about the site on the mountain thought they were being asked if they had been camping in the mountains before. Discuss the need for concrete tools with which to communicate, and how students started with the concrete and moved into abstract thoughts. Also discuss the idea of first setting up the concept and then making the point. In other words, first let your partner know you are talking about colors and the idea of favorite, then ask their opinion. Touch on the frustrations felt when we know what we mean and then expect the other person to understand us when we think we are being clear. This quickly leads us into discussing blame and how communications break down. The discussion is not closed to any one theme, as this exercise brings up all kinds of comments and thoughts to explore.

Last, demonstrate one way to conquer the question often perceived as the hardest, "What do you think is humankind's worst problem?" Explain that for a long time people thought this question too challenging to ask until one student proved otherwise. He drew five circles on the board representing faces, with two eyes and straight line mouths. He drew vertical lines between each of the faces, to indicate that each was a separate category. He then pointed to the first face and acted out an airplane flying overhead and dropping a bomb, then drew a mushroom cloud on the board. He walked over to the first face and drew four tears coming out of its eye. He then pointed to the second face and acted out a terrorist hijacking (using another student as "hostage"), and pointed on the map to the Middle East where a hijacking had recently occurred. He walked to the second face and drew two tears. After pointing to the third face, he mimed being a malnourished baby with protruding belly, who eventually dies. He pointed all over the world and drew numbers of children on the board to signify the enormity of this occurrence. He walked to the third face and drew three tears on the board. He walked to the fourth face, pointed and then drew and acted out many trees being cut down by bulldozers, factories dumping waste and killing fish, and many buildings covering the earth, crossing out the trees and animals as each building went up. He then walked back to the fourth face and drew

three tears. Then he pointed back to the first face and held his hands over his heart and made a pained face, pointing to the four tears and to himself.

Then he handed the chalk to his partner, pointed to all four faces and to the fifth space which was left blank for a new idea, shrugged his shoulders and pointed to his partner.

SUMMARY

All four of these exercises are used to get students to think about communication in a wider range of modalities and to let them know they have the capacity to communicate in depth without the use of words or signs. Encourage students to continue these exercises, or to try them with friends or family members, to make blindfolds and practice eating or getting dressed while wearing them. Books written by Fred Gywnne (1970; 1976) illustrate beautifully the importance of clarifying your concept instead of relying on words and are excellent for continuing discussion on the role of language and communication in our relationships. His books The King Who Rained and A Chocolate Moose for Dinner are about a young girl's misunderstanding of the words used in the world around her.

Another suggestion is to invite adults who are deaf-blind as role models to the classroom. We have found that this gives students an understanding greater then any exercise we have tried. Although the students who are developmentally delayed differ in cognitive process and life experience from those who are not developmentally delayed, they share the losses of vision and hearing. Adults who are deaf-blind can offer the most useful and complete information about methods, modalities, strategies and considerations regarding the dual sensory impairment of deaf-blindness. They also can provide for the students a model of what is possible. After meeting an adult role model students could more easily envision a full and meaningful life for someone who is deaf-blind.

References

Cokely, D., & Baker, C. (1980). American Sign Language: A teacher's resource text on curriculum, methods, and evaluation. Silver Spring, MD: T. J. Publishers.

Gwynne, F., (1970). The King Who Rained. New York: Windmill Books

Gwynne, F., (1976). A Chocolate Moose for Dinner. New York: Windmill Books

Kettrick, C. (1988, May). How to teach ASL. Paper presented in Seattle, WA.

Requests for reprints should be addressed to: Lyle T. Romer, Ph.D., University of Washington, College of Education; Lifestyle Planning Project, 1915 First Ave., #1, Seattle, WA 98101.

❖❖❖❖❖❖❖

From The Editor

John Reiman

As I move to the steward's role with this issue of *Deaf-Blind Perspectives*, I bring to friends, colleagues, and other readers of this publication my wishes for a fulfilling and abundant new year. Before proceeding with some thoughts on our future, I wish to acknowledge the extraordinary contributions to the evolution of this publication made by its first Executive Editor, Bud Fredericks. Bud's sagacious counsel and inspired leadership launched *Deaf-Blind Perspectives* and carried it forward. Were I not to have the luxury of a biweekly Scrabble game with the now retired Dr. Fredericks to discuss life and the world, I would feel terribly deprived of contact with a mentor and friend.

I envision the task ahead of us at *Deaf-Blind Perspectives* as challenging in three ways. First, I believe that the changing role of government in the lives of all Americans, not only those who are deaf-blind, compels us in this field to search out and define our mutual interests. In order to mount a common defense against governmental withdrawal of funding, this publication must present a cross-section of perspectives of all those who are deaf-blind, and, at the same time, it must not present some artificially homogenized picture. By learning to understand our different needs and interests and by acting as much as possible as one faction, we can stop competing for the constantly diminishing piece of budgetary pie allocated to people who are deaf-blind, their families, and the professionals who serve them. By working together for common needs, all will benefit.

Our second challenge at *Deaf-Blind Perspectives*, is to involve more people who are deaf-blind and their families as contributors to the publication. Nonwriters need not feel intimidated. Our editors welcome the opportunity to take otherwise acceptable (useful/relevant to the readership) pieces of writing, and adapt them to fit the style and structure of *Deaf-Blind Perspective's*.

Our third challenge is to achieve overall balance in the type of material we present. Our goal, even if not in every issue, will be to blend the academic with the anecdotal, the light with the heavy, the practical with the philosophical, and the emotional with the logical.

I invite the readers of *Deaf-Blind Perspectives* to tell me and our extraordinary Managing Editor, Bruce Bull, about your likes, dislikes and hopes for the future of *Deaf-Blind Perspectives*. Since we genuinely want to hear from you we have included a survey in this issue. We would appreciate your taking the time to complete and return it to us.

❖❖❖❖❖❖❖

Reader Survey

Dear Friend:

We always enjoy hearing from you. Many of you write, others phone or fax. We hope everyone will respond to this questionnaire. Your views and ideas matter to us. Knowing your interests will help decide what goes into *Deaf-Blind Perspectives*. Subscribers who receive *Deaf-Blind Perspectives* in alternative formats are especially encouraged to provide us feedback.

Please use this survey to express opinions about the publication, its contents, and what you would like to see in the future. We do ask some background questions about you; these are optional. It's always nice to know more about our friends, but your privacy is even more important.

In advance, thanks for helping us improve.

Bruce Bull
Managing Editor

❖❖❖❖❖❖❖❖

Tell Us What You Think About *Deaf-Blind Perspectives*

1. How would you describe your reading of *Deaf-Blind Perspectives?*
   - ❑ I read it cover to cover, every issue
   - ❑ I skim each issue reading a few articles
   - ❑ I rarely find the time to read the newsletter

2. How would you rank your interest in these types of features?
   (Also, please circle the three most important to you)

	very strong	strong	fair	minimal
a. Content/how-to articles	❑	❑	❑	❑
b. Descriptions of research projects/quantitative pieces	❑	❑	❑	❑
c. Personal stories and opinion pieces	❑	❑	❑	❑
d. Updates on policy/advocacy work	❑	❑	❑	❑
e. Calendar of Events	❑	❑	❑	❑
f. For Your Library	❑	❑	❑	❑

3. Would you be interested in a "Letters to the Editor" feature? Why or Why not?

_____

4. What other features would you favor? _____

5. What specific issues are of greatest interest to you?

_____

6. Compared to similar publications you receive, how is our format?
   ❑ much better ❑ about the same ❑ not as good

7. How would you like to see the publication improved?

_____

_____

8. What are your main sources of information in the field of deaf-blindness? *(check no more than three, please)*

- ❑ *Deaf-Blind Perspectives*
- ❑ parent group(s)
- ❑ professional journals
- ❑ conferences
- ❑ newsletters
- ❑ networking
- ❑ Internet, Deafblind Forum, and/or other on-line services
- ❑ other _____

9. How important is *Deaf-Blind Perspectives* to you in terms of keeping you informed about the field and its work?

❑ very important ❑ somewhat important ❑ not important

10. Would you prefer to download your copy of *Deaf-Blind Perspectives* electronically?

❑ yes ❑ no

11. Would you be interested in writing an article for *Deaf-Blind Perspectives*?

❑ yes_____❑____no _____ If yes, on what topic(s)?

_____

_____

12. Have you ever shared *Deaf-Blind Perspectives*? If yes, with whom?

❑ friends ❑ colleagues ❑ your library

other: _____ _____

13. What format do you receive?

❑ Braille ❑ Large Print ❑ Regular Print ❑ ASCII

14. Does the format meet your needs?

❑ yes ❑ no

15. What suggestions would you offer to improve the format?

_____

Tell Us About Yourself

16. During the last 12 months have you written a letter to indicate an opinion? If yes, to whom?

- ❑ to a newspaper
- ❑ to an elected official

During the last 12 months have you made a telephone call to voice an opinion? If yes, to whom?

- ❑ to a newspaper, television, or radio
- ❑ to an elected official

17. How did you first learn about *Deaf-Blind Perspectives*?

_____

_____

18. On occasion, would you be interested in being a reviewer of manuscripts for *Deaf-Blind Perspectives*?

- ❑ Yes. If yes, include your address below. List preferred content areas. _____
- ❑ No

19 Which category best describes you?

Mark appropriate categories (3 max.)

- ❑ Person or parent of person who is disabled
- ❑ Special education (e.g., teacher, aide)
- ❑ Administration (*e.g.*, Dept. of Ed., project director)
- ❑ Service provider (*e.g.*, social worker, group home)
- ❑ Technical assistance provider
- ❑ Higher education teacher/researcher
- ❑ Regular education (non Spec.-Ed.)
- ❑ Therapist (*e.g.*, OT/PT/speech)
- ❑ Teacher trainer
- ❑ Government personnel
- ❑ Medical professional
- ❑ Other _____

20. Please share any other information or suggestions that you would like the *Deaf-Blind Perspectives* staff to receive.

Thank You!!

Name (*optional*) _____

Address (*optional*) _____

_____

Telephone (*optional*) _____

E-Mail (*optional*) _____

Please tape closed

Please fold survey at this line

TRD 820

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 19 MONMOUTH, OR

POSTAGE WILL BE PAID BY ADDRESSEE

Bruce Bull, Managing Editor
Deaf-Blind Perspectives
Teaching Research
Western Oregon State College
345 N. Monmouth Ave.
Monmouth, OR 97361-9989

A Special Thanks

A lot of very uncertain things are going on in the United States Congress. Most federal budgets are not yet approved and some categories of funding are earmarked to be eliminated. The fate of funding for the Deaf-Blind Programs is also not clear but at least they are still on the table for consideration. The fact that they have survived this long can be attributed to several factors such as lobbying by parents, pressure from organizations, and a history of an effective program. However, the single most important factor has been the relentless presence of the National Coalition on Deaf-Blindness, specifically, Joe McNulty, Director of the Helen Keller National Center and Mike Collins, of the Perkins School for the Blind. they have hardly missed a single meeting in Washington, D.C. when the deaf-blind funding was being discussed. They have not used an "in your face" approach but by their mere presence (Joe has been practically commuting) they have been "in their space". Everyone connected with this field owe Joe and Mike a great deal of gratitude and we need to take the time to applaud them.

❖❖❖❖❖❖❖

Hand in Hand Publications from the AFB Deaf-Blind Project

The following promotional information on *Hand in Hand* was submitted to *Deaf-Blind Perspectives* by American Foundation for the Blind (*Deaf-Blind Perspectives* disseminates, free of charge, descriptive information on the products of relevant federal projects).—ED.

Three unique books and a videotape of essential materials for anyone who works with someone who is deaf-blind are the final result of the AFB Deaf-Blind project. This four-year federally sponsored project, conducted by the American Foundation for the Blind, was charged with developing self-study and in-service training materials to fill the existing gap in information and resources for teachers who work with deaf-blind children and youths. Under the rubric *Hand in Hand: Essential for Communication and Orientation and Mobility for Your Students Who Are Deaf-Blind*, project staff and editor Kathleen Mary Huebner, Jeanne Glidden Prickett, Therese Rafalowski Welch, and Elga Joffee focus on providing information and instructional strategies in communication and orientation and mobility (O & M) because these are the two areas most influenced by the presence of combined hearing and vision losses.

To ensure that the project was as broad as possible in scope, a national consortium with representatives from the major national service organizations concerned with the field of deaf-blindness offered guidance and worked with the project staff in developing objectives and principles. More than 30 expert authors contributed to the final publications, and many more reviewed the materials. A national field test of the draft materials was conducted by more than 120 teachers and other service providers in 46 states.

The guiding principles for all the *Hand in Hand* materials reflect contemporary thought on the education of students who are deaf-blind. Primary, is the understanding that all individuals who are deaf-blind can learn, communicate, and move with purpose. Therefore, the aim of all the *Hand in Hand* materials is to help teachers maximize students' development of skills to foster their independence. In addition, the materials emphasize the inclusion of families, including the student himself or herself, as well as all members of the educational team in delivering effective and successful services.

The following four *Hand in Hand* components can be used together as a comprehensive training program for teachers and other personnel or independently to educate staff, family, and community members.

Hand in Hand: Essentials of Communication and Orientation and Mobility for Your Students Who Are Deaf-Blind—A two-volume self-study text providing a comprehensive curriculum that explains how students who are deaf-blind learn and provides practical strategies for teaching, focusing on essential communication and O & M skills. Self-study questions and answers, wide margins for note-taking, technical appendixes, sample forms, glossary, and an extensive resource section maximize its usefulness as a learning and resource tool.

Hand in Hand: It Can Be Done!—An engaging one-hour video introduction to working with students who are deaf-blind, starring deaf-blind children and young adults as well as their families and teachers. It provides a graphic illustration of many of the principles and concepts in the self-study text. It is available in closed-captioned and audiodescribed versions.

Hand in Hand: Selected Reprints and Annotated Bibliography on Working with Students Who Are Deaf-Blind—A two-part volume, starting with a collection of 27 classic articles on working with youngsters who are deaf-blind that supplement the self-study text. The second half is a bibliography consolidating in one easy-to-use list, descriptions of invaluable print and audiovisual resources for teachers and families.

Hand in Hand: Essentials of Communication and Orientation and Mobility for Your Students Who Are Deaf-Blind: A Trainer's Manual—A step-by-step guide to using the *Hand-in-Hand* materials for in-service training. This manual provides sample blueprints for workshops; hints for working with adult learners; and an overview of and sample forms for needs assessment and evaluation of workshops.

The *Hand in Hand* materials are available from the American Foundation for the Blind. For prices or to order call (718) 502-7647. For more information on the AFB Deaf-Blind Project, call (212) 502-7653.

DB-LINK Fact Sheets

The National Information Clearinghouse On Children Who Are Deaf-Blind disseminates information through two primary methods. These are referred to by the project as reactive and proactive. Reactive, refers to the information provided consumers who contact DB-LINK with specific requests. Proactive dissemination refers to information gathered, formatted, and distributed in large quantities to consumers and potential consumers.

In addition to DB-LINK's contributions to *Deaf-Blind Perspectives*, DB-LINK has developed a number of fact sheets over the last year. Below is a short description of each of these. If you are interested in receiving one or more please contact DB-LINK. Additional fact sheets are being developed. These too will be announced in *Deaf-Blind Perspectives*.

DB-LINK
345 N. Monmouth Ave
Monmouth, OR 97361
Voice: (800) 438-9376
TTY: (800) 854-7013

Overview On Deaf-Blindness
by Barbara Miles

This overview provides fundamental information on deaf-blindness. Topics include causes, challenges, communication, orientation and mobility, education, transition, and family issues. The fact sheet is written for all audiences, especially parents, and professionals new to the field. Agency resources are listed and selected readings are referenced. (6 pages)

Recreation and Leisure
by Lauren Lieberman

Everyone benefits from recreation and this fact sheet shares practical information on how to get people who are deaf-blind with cognitive disabilities involved with recreational activities. The focus is on recreational activities for pre-adolescent children through adult. Included are the steps required to develop a recreational plan. Examples of recreation activities with different people who are deaf-blind. A listing of national organizations and additional readings is included. (6 pages)

Communication Interactions: It Takes Two
Adapted from the original written by Kathleen Stremel

This fact sheet provides an overview of how to interact with children who are deaf-blind. Examples of different communication opportunities are provided. Additional resources are listed. (4 pages)

Receptive Communication: How Children Understand Your Messages to Them
Adapted from the original written by Rebecca Wilson

Deaf-blind children communicate through a variety of receptive communication modes. This fact sheet helps the reader design a program that will assist the deaf-blind child, especially the child with additional disabilities, move up the ladder of communication complexity. Additional tips are given for sending messages and the expectations for the child's response. Additional readings are included. (5 pages)

Expressive Communication: How Children Send Their Messages to You
Adapted from the original written by Kathleen Stremel

This fact sheet provides information on the nature of expressive communication and the value of such communication. The continuum of expressive communication modes is described with examples of behaviors often modeled by children who are deaf-blind. The progressive nature of communication is discussed and considered via sensory, motor, and cognitive development. Suggested readings and additional resources are listed. (6 pages)

DB-LINK Family Resource Directory A Developing List of National Resources

Produced in cooperation with the National Family Association for Deaf-Blind, this is a directory of services written for families of children who are deaf-blind. National resources are described and contact information provided. Precut postcards and rolodex cards are included. (Due to printing costs, limited numbers of this publication are available. We ask that requests come only from families and direct service professionals.)

"Free To Be Me"

Joann Twitchell

Joann is the parent of two children with Usher syndrome. The names of participants and cities have been changed to respect the privacy of participants. —ED.

Usher Syndrome Family Weekend

2:57 a.m. Sunday Morning -

I've been awake for 45 minutes. My brain is running full power trying to sort and file the information and feelings it has experienced the past 2 days.

Family introduction session - Interpreters dressed in black. Do Marie and Alan want to use an FM trainer? Sure. OK. (They wear one every day at school "They are used to the staring people". - How do I know that? - no one stares at me - but my child is part of me and I also feel the stares.)

I feel the tenseness in the air as we wait for our turn to stand and introduce our family. Debbie and Bethany are first. I still can't believe we are both from Chicago and have to come to Tampa to meet. Bethany is confident as she signs. Each family stands. Some parents sign. Some kids sign. All interpreters sign - oops, brain says "not true." Some whisper Spanish. Barbara waves to Gretchen from the side. It's been 20 minutes. Time for interpreters to switch. Tag in. Tag out.

Marie is antsy. She is dying to get up and tell the room who she is! Gretchen picks up on it. So much non-verbal communication going on in the room. "Who wants to be next?" Marie's hand is dancing on the air. "Marie would you like to go?" Her head bobs up and own - YES! YES! She flits up to front and center stage. The atmosphere in the room is . . . hmm . . . what's a good word . . . accepting. Marie is feeling "FREE TO BE HERSELF. Free to be me." (It's a catchy phrase, but I wonder if it's true for me?) She's 11 years old. Will this group let me be who I am?

Parent meeting. The kids and teenagers are in separate groups in other rooms. I had to coax Marie and Bethany away form the T.V. to go to their meeting. "It's gonna be boring MOM!" "No, I saw paper and markers on the table - it looks fun!" "OK."

The paper and markers look fun to me. Parent meeting - "It's gonna be boring." I coax myself to go. I'm late - Doug is saving me a seat. I sit down in defiance with my arms folded across my chest. Will this group let me be me? Do they know how I feel? If they don't nobody does! I listen. It sounds familiar. One dad is explaining his personality. "I tell Alisha -Come on honey, we can do this - we can do anything." That sounds like Doug.

Debbie is talking. Telling them she didn't want to come. She didn't want to see what her daughter would become. She didn't want to see blindness. That sounds familiar to me. The unknown is better left unknown. Right?

Gretchen asks "What were your feelings about coming to this conference?" Did she really want to know how I felt? Well, here goes - what the heck - I'll tell the truth. I blurt out - "I didn't want to come." "Can you tell us why, Joann?" "Yeah - because they have parent meetings and ask you to tell how you feel." As the room erupts into a little laughter I feel my tension being released into a room of understanding people. I felt understood. I was FREE to Be Me.

Break for lunch. Alan is eating with Steven and his Mom and Dad. Alan is amazing. He seems to be soaking it all in. No communication barrier is gonna stop him. I watch Julie with her tactual interpreter - Is that what he's called? Anyway, she's talking with someone. She looks so . . ."normal". Her hair's combed, her clothes match - better than mine - she doesn't look deaf-blind. She looks . . . like Julie. I hear someone behind me saying "Who is that up there." I look up to the 8th floor and see 4 pairs of legs dangling through the railing. Those crazy teenagers! I look closer - It's 2 teenagers, an interpreter, and . . . Grandpa Mac! He is crazy! Doug says, "That's my Father for you." Now no one wonders why Doug and Marie are like they are. Mac is "Free to Be Me."

Hey backup - Did I just call that girl, "an interpreter?" That sounds like what Marie and Alan hear at school. "They get called, 'the kids with the hearing aids'." I'm sure the "interpreter" has a name. Why are they here anyway? Is the money good? Is there a fantastic story behind the black shirt and dancing fingers? Yes, I'm sure of it.

The communication process is so alive here. I watch Seth sign. Boy - it could be dangerous to stand too close to him while he's talking. His personality jumps and stops and fly's through his fingers - through his whole body. It's such a contrast to . . . say . . . Blake. He stands, pauses, and then the signs gently flow out. Almost like he's singing. It's beautiful to watch the communication. To watch the differentness. The sameness. I look at Marie and Bethany and my brain says: Different . . . Same . . . Different . . . Same.

I watch Curtis and Alan and Steven communicate with paper and pencil. Some sign, some voice - different. All love Ninetendo - same. Different. Same. It's good to be different. It's good to be the same. It's good to be . . . FREE TO BE ME!

❖❖❖❖❖❖❖

Announcements

Helen Keller Art Show

This is a call for art for the Helen Keller Art Show "Washington National Cathedral Exhibit" sponsored by Very Special Arts Alabama and CEC Division on Visual Handicaps. This invitation is for visually impaired, blind, or deaf-blind youth to submit artwork from their school system. Students may select the preferred art medium. The contest is open to school children of all ages. Each school system may submit up to seven pieces of art. Winning entries will be displayed at the National Cathedral from March 7 through May 27, 1996. At the conclusion of the tour of the exhibit, the artwork will be on exhibit at the Helen Keller Festival in Tuscumbia, Alabama, June 1996, and in senate or congressional offices.

Entries to be submitted by February 1, 1996.
For entry forms, contact:
Division on Visual Handicaps
Box 4107
Lubbock, TX 79409-1071

Free Information Packet

The Foundation Fighting Blindness is a national research organization that studies retinal degenerative diseases, including retinitis pigmentosa (RP) and Usher syndrome. Children with Usher syndrome are born with varying degrees of deafness and later develop RP—a degenerative disease that begins with night blindness and progresses to a loss of peripheral vision

To request a free packet that answers commonly asked questions and provides updates on the latest research please call the Foundation at:
(800) 683-5555 or
TDD (800) 683-5551

Calendar Of Events

Perkins National Deaf-Blind Training Project Schedule of Summer Institutes for 1996

Topic: *Strategies to Support the Inclusion of Learners who are Deaf-Blind in Schools and Communities*

Sponsoring University	Dates
Florida State University	June 23–27
Michigan State University	June 23–27
San Diego State University	July 14–18
University of Washington	July 21–25

All courses will be offered for graduate credit from the sponsoring university. For further information please contact your state Coordinator of Deaf-Blind Services or the Perkins National Deaf-Blind Training Project, (617) 972-7226.

1996 American Association of the Deaf-Blind Convention

The 1996 AADB Convention will be held on the campus of the University of Tulsa, Tulsa, Oklahoma **June 15–21** and hosted by the Oklahoma Deaf-Blind Sooners. The theme of for this convention is "Deaf-Blind People Can..." and will include workshops that show what the deaf-blind participants can do (dream, plan, work, etc.).

Contact:
AADB
814 Thayer Ave.
Silver Spring, MD 20910
Voice (800) 735-2258 TTY: (301) 588-6545
Fax: (301) 588-8705
E-mail: ydch5849@uct.uct.edu

Association for Education and Rehabilitation of the Blind and Visually Impaired 6th International Conference

St. Louis, Missouri is the site of AER's 6th International Conference to be held **July 20–24** at the Adams Mark Hotel. Included in the topics are; assessment of infants, mobility techniques for older persons who are blind, career counseling, family intervention, literacy issues of school age children, and the latest trends in technology.

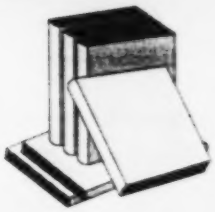
Contact:
AER
206 N Washington St. Ste 320
Alexandria, VA 22314
(703) 548-1884

5th Canadian Conference on Deafblindness

Held **May 8–11** at the University of British Columbia in Vancouver, B.C., Canada, this conference offers session speakers from all over the world and includes a variety of sessions with four full day Saturday sessions. These events provide the opportunity for an intense learning experience with four six-hour workshops which require preregistration within the general registration. The conference features five keynote addresses and over 50 concurrent workshop and poster sessions.

For information and registration packet contact:
Conference on Deafblindness 1996
Secretariat
UBC Conference Centre
5961 Student Union Blvd
Vancouver, BC Canada V6T 2C9
V/TDD: (604) 822-1050
Fax: (604) 822-1069
E-Mail: registration@abrock.housing.ubc.ca

36



For Your Library

Unless otherwise noted, the following information may be obtained by contacting DB-LINK at:
Voice: (800)438-9367 TTY: (800) 854-7013

Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities 1992. (A Parent's Guide, Update May 1992)

The article was written to help families learn how to get help for their young children with special needs. Answers are provided for the most commonly asked questions about early intervention services for children ages birth through 2 years old and special education and related services for children ages 3 through 5 years old.

Communication Systems and Routines: A Decision-Making Process

Stremel, Kathleen; Molden, Vanessa; Leister, Chrissy; Matthews, Jimmie; Wilson, Rebecca; Goodall, deVergne; Holston, Jan. University of Southern Mississippi, [1990]

The ultimate goal for children with any type of disability in the area of communication development is to assist the child, through social interactions and environmental arrangements, to be able to communicate in the most effective way possible, with a variety of people, and in a wide variety of social situations and environments. Knowing where to begin, the direction to take, anticipating some detours along the way, and knowing when when one has arrived are be based on a decision-making process. This manual covers the teaching of communicative behaviors, receptive communication and expressive communication, for children with vision, hearing and motor impairments via this decision-making process. Includes diagrams, charts, examples, and an Individualized Family Service Plan.

Dancing Cheek to Cheek : Nurturing Beginning Social, Play and Language Interactions

Meyers, Laura; Lansky, Pamela. -- Los Angeles: Blind Children's Center, [1992] 33 pages

This booklet is based on the research findings of a four-year study of ten babies with severe visual impairment. They had differing diagnoses, resulting in varying degrees of cognitive and motor disabilities. The goal of the research was to find techniques that parents and babies can use to successfully bypass some of the obstacles to the development of social, play, and language skills that are the result of lack of vision. Includes listings of activities that were successful and those that were not. This booklet may be ordered from the Blind Children's Center, 4120 Marathon Street, P. O. Box 29159, Los Angeles, CA 90029-0159, or by calling (213) 664-2153, (800) 222-3566,.

Interaction and Play

Matthews, Jimmie. — Hattiesburg, MS: University of Southern Mississippi, 1992. (Adapt-A-Strategy Booklet Series) 10 pages

Discusses interactions with people and objects at the reflexive and intentional behavior stages and encouraging social interaction through play.

Positioning and Handling

Yates, Cynthia. -- Hattiesburg, MS: University of Southern Mississippi, 1992. (Adapt-A-Strategy Booklet Series) 10 pages

Covers basic information about infant positioning and handling to develop motor skills. For availability information call:
University of Southern Mississippi, (601) 266-5135.

Guiding Principles for Interaction with Young Children who are Deaf-Blind

Anthony, Tanni; Greeley, J.; Gleason, Debbie. -- Revised. 1994. 2 pages

Eight suggestions for successfully interacting with young children who are deaf-blind. Suggestions for using toys and types of toys to use are included.

Handbook for Parents of Deaf-blind Children

Esche, Jeanne; Griffin, Carol. — Lansing, MI: Michigan School for the Blind, 1989 (revised) 25 pages

The handbook deals with basic information for parents to use in raising a child who is deaf-blind and answers many questions relating to parents and family. The goal is to help parents feel more confident in assisting with the growth and development of their deaf-blind child. Contains information about mannerisms, sitting, standing, walking, eating, dressing, toilet training, discipline, speech/language, auditory experiences, play and toys, and glasses and hearing aids. Available from DB-LINK.

Key Indicators of Quality Early Intervention Programs

Chen, Deborah; Haney, Michele. — Northridge, CA: California State University, 1994. Length: 2

This is a list of indicators based on a review of current literature on effective practices in early intervention. It reflect the unique learning needs of infants who are deaf-blind as well as the priorities of their families. Included is a model for promoting learning through active interaction.

Deaf-Blind Perspectives

- ❑ I enjoyed this issue of *Deaf-Blind Perspectives* but I am not on your mailing list. Please send future issues to the address below.
- ❑ I've moved! Please send future issues of *Deaf-Blind Perspectives* to my current address.
- ❑ I'm buried in interesting publications! Please remove my name from your mailing list.

Name: _____ Agency: _____

Street: _____ City: _____ State: ___ Zip: _____

Comments _____

_____

_____

Mark appropriate categories (3 max.)

- ❑ Person or parent of person who is disabled
- ❑ Special education (*e.g.*, teacher, aide)
- ❑ Administration (*e.g.*, Dept. of Ed., project director)
- ❑ Service provider (*e.g.*, social worker, group home)
- ❑ Technical assistance provider
- ❑ Higher education teacher/researcher
- ❑ Regular education (non Spec.-Ed.)
- ❑ Therapist (*e.g.*, OT/PT/speech)
- ❑ Teacher trainer
- ❑ Government personnel
- ❑ Medical professional
- ❑ Other _____

Please send my copy in:

- ❑ Grade 2 braille
- ❑ Large print
- ❑ Standard print
- ❑ ASCII

Mail to: *Deaf-Blind Perspectives* • Teaching Research Division • 345 N. Monmouth Ave. • Monmouth, OR 97361 • or call Randy Klumph (503) 838-8885, TTY (503) 838-8821, fax: (503) 838-8150, E-mail: klumphr@fstr.wosc.osshe.edu

Deaf-Blind Perspectives can be downloaded from Library 5 of the CompuServe Disabilities Forum. 1295

Deaf-Blind Perspectives is a free publication, published three times a year by the Teaching Research Division of Western Oregon State College. The positions expressed in this newsletter are those of the author(s) and do not necessarily reflect the position of the Teaching Research Division or the U.S. Department of Education.

Deaf-Blind Perspectives
Teaching Research Division
Western Oregon State College
345 N. Monmouth Ave.
Monmouth, OR 97361

Forwarding & Return Postage Guaranteed,
Address Correction Requested

Non-Profit Organization
U.S. Postage
PAID
Permit No. 344
Salem, OR

Deaf-Blind Perspectives

Volume 3, Issue 3 Spring 1996

Reflections, Comments, And Suggestions

Bud Fredericks

I have a need to explain why I am writing this article. A number of months ago, I decided to retire from Teaching Research and have since done so. When I made this decision, which also removed me from the editorship of this publication, Bruce Bull, the managing editor, asked if I would consider writing an article reflecting on the 25 years that I worked in the deaf-blind field. I foolishly agreed to do so. I even let one edition of *Deaf-Blind Perspectives* slip by without submitting anything, thinking that Bruce was merely being polite to an old guy who was leaving and that he would soon forget that he made the offer. Unfortunately he did not, and as he badgered me unmercifully for the written material, I realized it was not just a polite request. And so, here are my reflections.

My introduction to the deaf-blind educational world occurred in 1970 when Vic Baldwin and I were approached by the Northwest Regional Deaf-Blind Center to consult with their classroom programs, which were all housed in the Vancouver School for the Blind in the state of Washington. We had previously developed an effective classroom model for children with severe disabilities, and so we were asked to adapt that model for the children being served by the Northwest Regional Center. That was my introduction to the system that supported deaf-blind programs, and over the ensuing years, I directed early childhood, school age, and vocational projects for children and youth who are deaf-blind.

The deaf-blind world has changed significantly since 1970. At that time all educational programs were provided by regional centers, and most instruction occurred within residential or institutional settings. The passage of Public Law 94-142 was still a number of years away, and so if parents chose not to send their child to an institutional setting, they maintained him or her at home.

Yet the regional centers were not oblivious to the needs of these parents. On the contrary, many of them conducted extensive training sessions and published much material for the benefit of parents who were keeping their children at home. I was reminded of this during the recent Deaf-Blind Symposium when I was given the task of reviewing the literature regarding parent involvement. In the early seventies there was a plethora of publications designed for parents. It is interesting to note that more material for parents of children who are deaf-blind was written prior to the passage of the public law that empowered parents in the educational system than immediately thereafter. In fact, only recently has there re-emerged a focus on the needs of parents of children who are deaf-blind.

The regional centers were the strongholds for deaf-blind education for a number of years, but in those early years, two factors stood out. We have already mentioned the first—that not all children who were deaf-blind were educated. Even with the passage of PL 94-142, it was a number of years before all children found their way to a classroom.

The second factor was that the number of children who were identified as deaf-blind was not very accurate. Although some regions engaged in extensive outreach activities, these were sporadic and uneven, often neglecting some of the more remote states.

And so, things have changed significantly in these past 25 years. Under the leadership of Dr. Victor Baldwin, the accuracy of the deaf-blind count has improved tre-

In This Issue

Reflections, Comments, And Suggestions 1
Bud Fredericks

Adapting Games, Sports and Recreation for Children and Adults who are Deaf-blind 5
Lauren J. Lieberman

For your Library 8

NFADB is Making a Difference 8
Mary O'Donnell

Calendar of Events 9

When Retinitis Pigmentosa and Hearing Loss Happen Together 10

Utah Update 10

Internet Connections 11

mendously (U.S. Department of Education, 1995). The only disputable area now focuses on whether certain children who function as though they are deaf and blind and upon whom accurate assessments cannot be made should be included in the annual census.

Over the past 15 years there have been significant changes in the education of children who are deaf-blind. No longer, except in the Northeast and two states in the North Central area, do regional centers exist. Instead, developing, maintaining, monitoring, and improving educational services has become a state function, as well it should. Moreover, each state has, through federal fiat, a person who is responsible for ensuring that such education is adequately delivered within the state. Just as with the deaf-blind regions in former times, however, there is currently wide variation among the states as to the quality of the educational services provided.

Children who are deaf-blind are no longer primarily educated in residential or institutional settings. Instead, they are found primarily in public school settings throughout the country. They are included in early childhood classes, are found in a variety of educational environments within the public school, and are generally provided transition services from school to adulthood.

Some things do not change. In 1970, the primary need in many locations was for educators who were trained to provide quality services for children who were deaf-blind. That need persists in many locations today. Despite the fact that some very excellent curricular materials have been developed, despite the fact that we continually improve the quality of our technical assistance and inservice training, and despite the fact that more trained educational staff are available than ever before, we still have significant shortages of staff who are trained to work with children and youth who are deaf-blind. These shortages exist primarily because students who are deaf-blind are scattered throughout the educational systems of our country.

There are those professionals today who maintain that this problem of population scatter could be solved if we reinstituted centers where students who are deaf-blind could be congregated and educated. Given the distribution of children and youth who are deaf-blind, this would mean a return to institutional settings, albeit I believe that those who make these proposals envision a different type of institutional setting, one that is smaller and serves a smaller region.

Certainly, if that is what parents want, then we should consider it. However, Fredericks, Ford, and Rafalowski-Welch, (1995) recently completed a survey of parents throughout the United States.

Deaf-Blind Perspectives
Volume 3, Issue 3
Spring 1996

◆◆◆◆◆◆◆◆

Executive Editor
John Reiman
Teaching Research

Managing Editor
Bruce Bull
Teaching Research

Production Editor
Randy Klumph
Teaching Research

Consulting Editors

Janice Adams, Deaf-Blind Consultant; Harry Anderson, Florida School for the Deaf and Blind; Vic Baldwin, Teaching Research; Chigee Cloninger, University of Vermont; Mike Collins, Perkins School for the Blind; Bruce A. Dalke, Teaching Research; June Downing, California State University – Northridge; Joyce Ford, Parent; Bud Fredericks, Editor Emeritus; Jay Gense, Mid-Oregon Regional Program; Karen Goehl, Indiana Deaf-Blind Project; Lori Goetz, San Francisco State University; Monica Kleeman,Perkins School for the Blind; Betsy McGinnity, Perkins School for the Blind; Barbara A. B. McLetchie, Boston College; Kathy McNulty, Helen Keller National Center; Robert Moore, Parent; Marianne Riggio, Perkins School for the Blind; Art Roehrig, Gallaudet University; Rosanne Silberman, Hunter College.

◆◆◆◆◆◆◆◆

Deaf-Blind Perspectives considers all unsolicited manuscripts and employs an anonymous review process. Manuscripts should adhere to *American Psychological Association* standards. Send both a printed copy and a disk copy (preferably DOS format) to:

Deaf-Blind Perspectives
Teaching Research Division
345 N. Monmouth Ave.
Monmouth, OR 97361
(503) 838-8403
TTY (503) 838-8821
fax (503) 838-8150

www.tr.wosc.osshe.edu/tr/dbp

More than 900 usable responses were obtained. Approximately 50% of these parents indicated that they wanted their child who was deaf-blind to be included in a regular educational setting. That number seems to be increasing as parents are exposed to additional information about how such inclusion can be effectively accomplished. These data represent about 10% of the parent population. If they constitute a representative sample, then for at least half the deaf-blind population the concept of a return to center education is no longer viable.

If I were to pinpoint the one concept, event, movement, or trend in the last 25 years that most significantly affects deaf-blind education, other than the passage of PL 94-142 and PL 99-457, I believe it would be this strong advocacy for inclusion. This advocacy has had two results: More children who are deaf-blind are being included in public school settings, and many of these students are totally included in regular education classrooms.

Strong advocacy for inclusion has also resulted, however, in some divisiveness within parent groups and among professionals. Many parents vehemently oppose the inclusion of their child while others are strong advocates. Professionals seem to be arrayed along a continuum. At one extreme are the proponents of full inclusion. At the other end of the spectrum are professionals who favor more segregated settings. Between these two extremes professionals take a variety of stances that usually entail partial inclusion with certain conditions or supports.

"I have two concerns and several suggestions about what is occurring in the inclusionary movement."

I have two concerns and several suggestions about what is occurring in the inclusionary movement. I strongly oppose the inclusion of students who are deaf-blind (or other students with disabilities) unless there is a well-coordinated system of support that ensures quality education for the student. I believe that, for inclusion to be effective for students who are deaf-blind, one must ensure that a system of continual communication is available with peers and staff throughout the school day. The use of a paraprofessional interpreter-tutor in all educational settings for students who are deaf-blind is proposed as a way to achieve that system of continual communication (Ford & Fredericks, 1994, 1995; Greenfield, Ford, & Fredericks, 1995).

My second concern about the inclusionary movement is the paucity of good research about its effectiveness. Social interaction with peers is usually cited as the primary benefit of inclusion, and that certainly is very important. However, where are the data that demonstrate that inclusion is the best type of placement for the child's acquisition of knowledge and skills? For that matter, where are the data that demonstrate a segregated setting is preferable for learning to occur?

In the Fredericks, Ford and Rafalowski-Welch survey, (1995) 50% of the parents favored inclusion. However, 39.9% of the parents favored their child being educated in a residential setting or a separate special education classroom. The wishes of these parents must also be honored, and advocacy for quality services for them should be comparable to the advocacy generated by inclusionary proponents.

Too often parents are presented limited options. Professionals who favor one type of educational placement over another frequently portray to parents only the benefits of their preferred form of education. School districts often offer parents only those options that are currently available, seldom discussing the establishment of a new alternative. Consequently, parents make decisions for their children based on limited information as it is filtered to them by well-meaning professionals or budget-bound school systems.

In 1970, the regional centers had few alternatives to offer because other options had not yet been developed. Today, we have the potential of a wide range of educational possibilities. Parents should be made knowledgeable about all of them so that they can intelligently choose what they think will be best for their child. They should not be persuaded by a professional's preference or limited by a school district's failure to present a full array of options. I believe that one of the functions of the 307.11 grantee with support from TRACES, TAC, and DB-LINK is to ensure that parents are presented with an unbiased portrayal of the educational options that should be available. This must include a description of the benefits and disadvantages of each option.

The 1970 regional centers recognized the need for active involvement with parents. They made what they considered to be significant efforts to assist parents. They developed curricular materials and conducted workshops for parents. Although many 307.11 grantees do conduct workshops for parents, I believe they are not much improved over those

offered in the early 1970s. I believe that a major portion of our technical assistance efforts should be focused on parents. Family support services should receive equal status with the training of school-based personnel. Families should be helped to develop strong parental organizations in each state so that they can become viable partners with professionals to effect systems change.

I am confident that the latter statement is some form of governmental or bureaucratic heresy. When I once suggested to a prominent division head within the United States Department of Education the need for TRACES to provide proactive support for the establishment and maintenance of statewide deaf-blind parent organizations, I was immediately informed that TRACES could not do such a thing because the federal government was already funding parent organizations in each of the states.

"Family support services should receive equal status with the training of school based personnel."

Being a parent of a person with disabilities, I am undoubtedly biased, but I believe that parents are the key to the successful improvement of services to children who are deaf-blind. This is historically true for other disability groups, such as mental retardation, traumatic brain injury, and, most recently, emotional disturbance. Parents are traditionally more committed advocates and become especially effective when teamed with empathetic professionals. Parents can better influence legislators; and through networking, they can spread those changes throughout the country.

Let me illustrate the effectiveness of parents with legislators. A number of years ago prior to the federal passage of PL 99-457, which provided early intervention services for children with disabilities, a number of us in Oregon were anxious to have state legislation that would provide early childhood services for all children with disabilities. For two sessions of the legislature, professionals presented research data that indicated the benefits of early childhood education and many parents with their children with disabilities appeared before the same legislative committees asking for the passage of such legislation. For two sessions of the legislature, we failed. As the third session of the legislature approached, we once again marshalled our forces and were arranging for even more parents to testify. A few days before the scheduled testimony, I received a phone call from the chair of the legislative committee. He said in effect, "Let me assure you that during this session of the legislature we will pass the early childhood legislation. Please do not bring all those parents with their children to testify any more. They have us convinced."

Technical assistance is about creating change. In the disability arena it is parent-professional partnerships that have created the greatest changes. At the local public school level, these partnerships have allowed children to be included in public schools which previously adamantly rejected them. At the state level these partnerships have rewritten policy that ensures adequate education for children who are disabled. At the national level, laws such as PL 94-142, PL 99-457, and the Americans for Disabilities Act were achieved because of close parent-consumer-professional partnerships. Therefore, if parent-professional partnerships are the vehicles that have created the most significant changes in the disability world, it seems logical that any technical assistance effort that seeks to effect change needs to include parents. And they should be included in the whole process—from planning through implementation.

As previously indicated, I recognize that many 307.11 grantees, often in cooperation with TRACES, orchestrate workshops for parents, conduct summer camp experiences, and provide individual assistance for selected parents. But TRACES evaluation data indicate that the bulk of both TRACES and 307.11 technical assistance focuses on teachers and other professional staff. I suggest that parents should be included in these training sessions. I believe that 307.11 advisory boards should consist primarily of families of children who are deaf-blind. And finally, I believe that statewide deaf-blind parent organizations should be developed in every state and that 307.11 grantees should be in active partnership with those organizations, offering assistance as necessary.

We have come a long way since 1970. We have more and better trained professionals; we have a wider array of service delivery options; and we have both a national clearinghouse and a national system of technical assistance.

We still have a long road to travel. In my opinion, we need more professionals trained to serve children who are deaf-blind; we need each child in school to have an interpreter-tutor; we need a system of advocacy that ensures that the current congressional threats and failures to increase funding

to match the growth of population and inflation will never again occur. The path we have to travel to achieve these goals can be shortened and made smoother if we recognize and put into practice the primacy of parents in selecting the place and method of educating their child. In addition, we need to build strong parent-professional partnerships that are vigorously supported by dynamic parent organizations in each state.

References

Ford, J., & Fredericks, B. (1994). Inclusion for children who deaf-blind. Network, 4, 25-29.

Ford, J., & Fredericks, B. (1995). Using interpreter-tutors in school programs for students who are deaf-blind. Journal of Visual Impairment and Blindness, 89, 229-234.

Fredericks, B., Ford, J., & Rafalowski-Welch, T. (1995). [Survey of parents of children who are deaf-blind] Unpublished raw data.

Greenfield, R., Ford, J., & Fredericks, B. (1995). You and Me: The Role of the Interpreter Tutor (Video, 19 minutes). Monmouth, OR: Teaching Research Publications.

U.S. Department of Education, Office of Special education programs. (1995). Seventeenth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act. Washington, DC: Author

❖❖❖❖❖❖❖❖

Adapting Games, Sports, and Recreation for Children and Adults who are Deaf-Blind

Lauren J. Lieberman
SUNY Brockport

With the loss of sight and hearing, an individual's sensory input and experiences are reduced and overall development may be delayed. As a result, limits or predetermined expectations are sometimes placed on individuals who are deaf-blind by parents, professionals, agencies, and people who are deaf-blind themselves. This is equally true regarding recreational activities. Creative adaptations can alter recreation activities and programs so they will meet unique needs and provide fun and healthy exercise for all who participate. The purpose of this article is to encourage parents, teachers, professionals, therapists, and consumers, to set up and adapt recreation activities and programs to meet the needs of all children and adults.

Important Rules

As for any other child or adult, the expectations for the person who is deaf-blind should be high. To provide every opportunity for the person who is deaf-blind to meet these high expectations, there are some important rules of thumb to follow when developing and adapting activities.

- Utilize the concept of Ecological Task Analysis (Davis & Burton, 1991). Ecological Task Analysis suggests that aspects of motor performance emerge from the constraints of the performer, the environment, and the task. Manipulating one or more of these three constraints will move the individual towards success. Participants should be afforded the opportunity to use a variety of equipment, and be given choices about how to optimally perform the desired activity. This will allow the individual, when possible, to have input on the type and extent of adaptations made.
- Link movement to language (Van Dijk, 1966). Once the child knows the movement and what it is called, he or she has the potential to execute the skill independently.
- Remember that partial participation is better than no participation (Block, 1992). Even moderate, significant, or total physical assistance to participate in an activity, is better than no participation at all. The person assisting can be a peer, sibling, teacher, or volunteer.
- Always begin with the smallest amount of assistance that will ensure desired performance and success (Lieberman, 1995). Then, assistance and adaptations should naturally be faded out as the person begins to exhibit more independence.
- Monitor adaptations as necessary to ensure success.
- Refer to the activity by its common name. If several adaptations have been made to the game of golf (e.g., using a different ball, a different club, and targeting holes closer together) it should still be referred to as golf. If we call activities different names because they differ from the original version, then individuals who are deaf-blind will not have the satisfaction of knowing that they can really play golf

and may miss opportunities to converse about, and participate in, the activity with others who refer to it by its common name.

- Modify activities in a way that enables students without disabilities to assume the impairment of the individual with a disability (Winnick, 1978). For example, simulating a visual impairment or participating in activities in a wheelchair, will increase the sensitivity of individuals without disabilities: Teachers will better adapt activities for their students, peer tutors will better understand how they need to work with the student who is deaf-blind, and same age-peers will better understand why each activity is adapted.

Adapting Activities

The following issues need to be considered when making adaptations:

- **The Individual**
  - › Involve the individual in dererming adaptations
  - › How does the person ambulate?
  - › Is the activity age appropriate?
  - › What are the individual's characteristics, preferences, and behaviors?
  - › What are the individual's favorite activities?
- **The Activity**
  - › Playing Area or Environment
    - » Make the area larger or smaller
    - » Make visible boundaries
    - » Lower the height of goals
    - » Orient the individual to the activity area
  - › Playing Object
    - » Make the object bigger or smaller
    - » Make it softer or harder
    - » Make it audible or bright
    - » Change the texture of the object
    - » Make the object heavier or lighter
    - » Increase the size of the target
- **The Game**
  - › Change the rules of the game
  - › Change the objective of the game
  - › Increase the tactile cues
  - › Add guidance or a leader
  - › Change the number of players
  - › Increase chances
  - › Decrease time of activity or add rest periods
  - › Reduce repetitions or slow the pace
- **The Players**
  - › Change the role of the players
  - › Limit or add responsibility
  - › Modify demands on the student
  - › Decrease competition
- **Other Considerations**
  - › What can you do to make the student more successful?
  - › Will the individual achieve success with minor adaptations?
  - › Will the child have success with no adaptations?
  - › How can you add a cognitive component to the game?
  - › How can you ensure peers or siblings will also enjoy the activity?

Examples

Eddie is a 15-year-old boy with Congenital Rubella. When asked what he wanted to do for recreation, he said he wanted to learn how to ride a unicycle. Despite our apprehension, we set up a program for him. The activity was age appropriate and matched his ability level. By using a guide wire and physical assistance for support, he learned how to ride, and within 3 months he was riding the unicycle independently.

Cory is a 17-year-old Deaf woman with a visual impairment, and cerebral palsy. She uses a wheelchair for ambulation, and has travel vision with corrective lenses. Cory lives in an environment which has long winters. Cory was introduced to cross-country skiing by her high school physical education teacher. She sat in a sled, and used cut-off poles for propulsion. She was given occasional directional cues by her teacher or a friend in order to cross-country ski successfully. When she moved to a group home which offered cross-country skiing every week, Cory became involved because she knew she could ski with minor adaptations. She now skis regularly with her friends and family.

Margo is a teenager who is visually impaired and deaf. She wanted to play softball with her brother

and their friends. They discovered that by placing large orange cones at each base, placing a bright red line of tape from one base to another, and allowing Margo to bat off a tee, she was successfully included in the game. These adaptations were developed over time as needed.

Glenn is a 16-year-old boy who is deaf, visually impaired, and mentally retarded. Glenn attends his local high school. His physical education teacher found a wonderful way to adapt volleyball and at the same time increase the excitement for the other children. The ball used was a beach ball which is brighter and slower than a volleyball. The kids were permitted to hit the ball up to three times, let the ball bounce twice, catch it if they needed, walk to pass the ball, and have no limit on how many people touched the ball. Points were scored if the other team hit the ball under the net, out, or if the ball bounced more than two times or rolled. All the kids loved it and the volleys were so long they were out of breath at the end of each point. Although many adaptations were made to the game, they still called it volleyball.

Janet is a 12-year-old girl who is deaf-blind, has hemiplegic cerebral palsy and is ambulatory. She wanted to get involved in her neighborhood hockey games which are always played in her cul-de-sac with her peers from school. Her older brother wanted her to be involved, so together they discovered what would work. They played with a frisbee which was brighter and slower than the ball they were previously using. The frisbee had to be touched by each player before they could score (which enabled all the children to be active participants). Janet had a buddy who physically assisted her and communicated to her where the frisbee was. When Janet was hitting the frisbee, the other team had to count to five before defending her. The game was a big hit and soon they even made a frisbee hockey club! Through partial participation, Janet was an active member of her team.

Dereck is an 11-year-old boy who is deaf-blind and has ADHD. The kids on the playground always played kickball and he really wanted to play. A student-teacher found out what it took to include Dereck. The kids had a choice to kick from a pitch or to kick a stationary ball. Dereck kicked the stationary ball and a friend guided him around all the bases. The friend who was guiding Dereck let him know through sign when to kick the ball, when to run, and when he passed each base. Whenever anyone kicked the ball the kids in the outfield retrieved the ball, lined up front to back and passed it over and under until the entire team touched the ball. When it arrived at the last child, that child yelled "stop." The person who was running stopped and counted how many bases he touched. If he made it to third, then he made three points for his team, if she ran around two times all the way to home plate then eight points were earned. This continued until each person on the team had a chance to kick, then the teams switched. Dereck and his peers loved this game because there were no outs and it was an individual as well as team oriented game.

Chris is a 6-year-old boy who is deaf-blind. His kindergarten class often plays twister for a socialization and body awareness activity. Chris's teacher called DB-LINK (The National Information Clearinghouse On Children Who Are Deaf-Blind) and they gave her a great idea. She took a donated queen-sized sheet and traced rows of circles, squares, triangles, hearts, and stars. On top of the shapes she traced glue, and on top of the glue she sprinkled different colored glitter for different shapes. She made a spinner to match the tactile twister game and even brailled it so Chris could be the caller. The interpreter signed the commands to Chris, and voiced when he was the caller. The kids in the class loved it and were further challenged not only to know the colors but also the shapes during the game!

Jake is a 7-year-old boy with Congenital Rubella and cognitive disabilities. His inclusive first grade class was working on locomotion, directionality, and color identification. His physical education teacher decided to play the game Bell Balloon Bash (Lieberman & Cowart, in press). Jake chose his own colored balloon which had bells inside. He was shown different locomotor skills by a peer to get to the balloon which was a visible 10-12 feet away. When he arrived at the balloon he was shown how to kick it using verbal and physical assistance. He then, with continued verbal and physical assistance, chased the balloon using different locomotor skills. He was given feedback by the teacher immediately following appropriate performance (McInnes & Treffry, 1982). Jake continued this activity throughout the unit and slowly decreased his need for physical assistance.

Adaptations Work!

We need to let people know about adaptations that work. As we tell success stories, we raise others' expectations, and help them learn how to adapt recreational activities to people who are deaf-blind or have multiple disabilities.

For example: Eddie Martinez who is deaf-blind was a star in the Eastern Athletic Association for the Blind track and swim meets; Riley Ford is successfully included in elementary physical edu-

cation in Idaho; Gabriel Labossier is deaf-blind and has been actively involved in cross country skiing, biking, and track activities; Harry Cordellos is a successful water skier and is blind; Tricia Zorn is blind and has won medals for swimming at the paralympic games in Seoul, Korea; Kelly Butterworth is deaf and was on the US downhill team for the World Games for the Deaf in Finland; and Dacia Hirsch is a World Class horseback rider.

It is also important to share the recreational successes of the individuals in your school, neighborhood, or home. Make a video, write an article for the school newspaper, send your story to *Deaf-Blind Perspectives*, or make an announcement on your local radio station. Successful participation in recreation, sport, and physical education is possible and that needs to be known!

References

Block, M. (1992). What is appropriate physical education for students with profound disabilities? Adapted Physical Activity Quarterly, 9, 197-213

Davis, W. E., & Burton, A.W. (1991). Ecological task analysis: Translating movement behavior theory into practice. Adapted Physical Activity Quarterly, 8, 154-177.

Lieberman, L.J. (1995). Recreation for individuals who are deaf-blind. Deaf-Blind Perspectives, Monmouth; OR: DB-LINK.

Lieberman, L.J., & Cowart, J.F. (in press). Games for People with Sensory Impairments: Strategies for Including Individuals of All Ages. Champaign, IL: Human Kinetics.

McInnes, J.M., & Treffry J.A. (1982). Deaf-Blind Infants and Children: A Developmental Guide. Toronto: University of Toronto Press.

Van Dijk, J. (1966). The first steps of the deaf-blind child towards language. International Journal for the Education of the Blind, 15(1), 112-115.

Winnick, J.P. (1978). Techniques for integration. Journal of Physical Education and Recreation, 49, 22.

❖❖❖❖❖❖❖❖

Recreational Resources For Your Library

Block, M.E. (1994). A teacher's guide to including students with disabilities in regular physical education. Baltimore: Paul H. Brookes.

Ideas for assessment, programming, and inclusion techniques of children in preschools, and elementary, and secondary schools.

Dell, S., & McNerney, P. (1992). Art and games: Sensational experiences for students with deaf-blindness. East Providence, RI: Meeting Street Center.

An innovative book that offers art, interaction, and movement activities.

Kasser, S.L. (1995). Inclusive games: Movement fun for everyone. Champaign, IL: Human Kinetics.

Many games and activities for inclusive settings. Geared toward individuals with any disability.

Lieberman, L.J., & Cowart, J.F. (in press). Games for people with sensory impairments: strategies for including individuals of all ages. Champaign, IL: Human Kinetics.

Games, sports, and activities that can be immediately played by any individual. Adaptations for individuals who are blind, deaf, deaf-blind, or multiply disabled. Includes how to play goal ball and beep baseball.

Lieberman, L.J., & Downs, S.B. (1995). Physical education for students who are deaf-blind: A tutorial. Brazilian International Journal of Adapted Physical Education and Recreation. 2, 127-143.

Teaching techniques, strategies for participation, instruction on how to set up peer tutoring, and motor and fitness assessment ideas.

Lieberman, L.J. (1993). Project S.I.M.P.L.E.: Activities for individuals with sensory impairments and multihandicaps. In S. Grosse, & D. Thompson (Eds.) Play and recreation for individuals with disabilities: Practical pointers. Reston, (pp. 80–88). VA: AAHPERD.

Includes pictures as well as providing teaching strategies for these activities.

Smith, T.B. (1994). Guidelines: Practical tips for working and socializing with deaf-blind people. Burtonsville, MD: Sign Media Inc.

Gives ideas on the types of recreational activities often preferred by individuals who are deaf-blind.

NFADB is Making a Difference

Mary O'Donnell, President

The Board of Directors of NFADB (National Family Association for Deaf-Blind) continues to work toward our 1995-96 organizational goal of strengthening our foundation, organization, and performance. Training for our board members is a centerpiece at each of our meetings and enables us to maximize personnel and resources. Time management, motivating parent groups, and advocacy are this year's topics.

We have developed and refined the "Regional Director's Handbook" into a useful tool. It contains a wealth of information and resources which will enable the regional directors to be more efficient and effective in serving the people in their regions. Our "Policies and Procedures Manual" provides the structure and guidelines NFADB needs for a smooth operation. Both manuals will continue to be "works in progress."

We are also in the process of developing a comprehensive database that will connect parents to other parents and to professionals to facilitate quick and

BEST COPY AVAILABLE

smart attention to an issue and/or need. And throughout the fiscal year beginning Oct. 1, 1996 NFADB will be collaborating more formally with DB-LINK to share and disseminate information, specifically to families.

NFADB continues our close affiliation with the National Coalition on Deaf-Blindness. Together we have made an enormous impact on the course of legislative action in Washington. Under the leadership of the NFADB Legislative Committee, our Board and membership have successfully informed our Congressional representatives of the unique impacts of deaf-blindness and of the specific needs of our family members. Our membership and friends have responded in large numbers. The results have been so positive that we will continue to expand the network of folks who will respond in short order to any issues on deaf-blindness. We are grateful to Coalition members for their efforts on behalf of our children.

The success and scope of our outreach and efforts on behalf of our children are enhanced by the response of our members and the growth of the Association. Our ultimate goal is to reach every family with a member who is deaf-blind so that we may support each other's fulfillment of dreams. We are especially proud of our trio-annual newsletter *News From Advocates for Deaf-Blind*. We will continue to provide information on issues that families should be thinking about.

NFADB hopes to continue to make positive contributions to the quality of family life. Our regional directors and Executive Committee members are making efforts to attend conferences, regional meetings and parent association meetings—wherever parents are—in every state to offer NFADB support and assistance. We welcome the opportunity to work with and for you.

NFADB
111 Middle Neck Rd
Sands Point, NY 11050-1299
(800) 255-0411 ext. 275

❖❖❖❖❖❖❖❖

Calendar of Events

Communication Intervention for Children with Disabilities
July 22–24, 1996
Seattle, WA

This workshop is designed for teachers and speech-language pathologists who provide or design communication instruction for nonverbal children with severe and multiple disabilities.

Alexandra Slade
WA State Univ. Portland Projects
1818 S.E. Division St.
Portland, OR 97202

(503) 232-9154 (V)
(503) 232-6423 (Fax)
slade@vancouver.wsu.edu

VISIONS 1996: Foundation for Fighting Blindness Biannual Conference
August 17–20, 1996
Washington, DC

This year's theme "Commitment to a Cure" will recognize the 25 years of dedication to find cures for retinal degenerative diseases

Foundation for Fighting Blindness
Executive Plaza I, Ste 800
11350 McCormick Rd
Hunt Valley, MD 21031-1014
(800) 683-5555

Partners at Work: Advancing Options and Independence
26th Southeast Regional Institute on Deafness
November 2–5, 1996
Nashville, TN

Information will be presented on advanced and innovative programs, products and services available to foster the options and independence of individuals who are deaf, deaf-blind, or hard of hearing.

Sherri Rademacher
Tennessee Council for the Hearing Impaired
400 Deaderick St. 11th Floor
Nashville, TN 37248-6300
(615) 313-4911 (V/TTY)
(615) 741-6508 (Fax)

Coming of Age: Celebrating 30 Years of Professionalism
1997 Biennial ADARA Conference
May 20–24, 1997
Milwaukee, Wisconsin

Five days of workshops and mini-seminars will be conducted by professionals exploring current issues of awareness, access, education, employment, mental health and other areas related to deaf, hard of hearing, and deaf-blind issues.

Sue Kay Bailey
Independence First

600 W. Virginia St.
Milwaukee, WI 53204

(414) 291-7520 (V)
(414) 291-7525 (TTY)

4th IAEDB European Conference on Deafblindness: Discovering the Wor(l)d Together
July 19–24, 1997
Madrid, Spain

Conference includes plenary sessions, workshops, 9th European Usher Syndrome Study Group, Family camp, exhibition, and social activities.

4th European Conference Secretary
Módulo de Sordociegos
C.R.E. Antonio V. Mosquete (ONCE)
Paseo de la Habane, 208
28036 Madrid (ESPAÑA)

(34) (1) 3 45 36 97 (ext. 237)
(34) (1) 3 50 79 72 (Fax)

❖❖❖❖❖❖❖

Traces

When Retinitis Pigmentosa and Hearing Loss Happen Together

Cheryl Kennedy
University of Pittsburgh

On March 5, 1996 the video teleconference "When Retinitis Pigmentosa and Hearing Loss Happen Together: Meeting Educational Needs," was broadcast from the Distance Learning Center of the Pennsylvania Instructional Support System. The purpose of the video teleconference was to increase understanding of the characteristics of learners with Retinitis Pigmentosa occurring simultaneously with hearing loss, and to increase awareness of educational strategies and adaptations for students with Usher Syndrome. Planning and implementation of the teleconference was a follow-up activity for the Northeastern and North Central Regional TRACES Project 1995, "Usher Syndrome Planning Meeting."

Over eighty educators, adult service providers, consumers, and families viewed the teleconference. In addition to Pennsylvania, fourteen other states also viewed the conference via satellite. The Pennsylvania Deaf-Blind Project offered onsite conference participants additional technical assistance (e.g., onsite consultation, workshops for teams of service providers). Out-of-state downlink site participants were advised to contact their state or multistate Deaf-Blind Project personnel to request follow-up technical assistance.

Copies of the teleconference are available on video from the Distance Learning Center of the instructional Support System of Pennsylvania. Contact Jill Bortmess at (412) 961-0294. The cost of the videotape for out-of-state residents is $25.00 and $12.00 for Pennsylvania residents.

Update on Utah's Funding of Services for Children With Dual Sensory Impairments

Paddi Henderson
TRACES Western Region

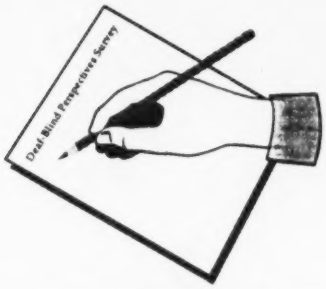
The Fall 1995 issue of *Deaf-Blind Perspectives* discussed the development of the Utah State Plan for Services to Children and Youth with Dual Sensory Impairments and Their Families. Since the publication of the article, the Utah State Board of Education made a request for $925,000 from the 1996 Utah State Legislature to implement the services.

The Utah legislature, after a great deal of testimony from parents and professionals, displayed its support for specific categorical deaf-blind services by providing a total of $800,000 ($200,000 in ongoing and $600,000 in one-time funds) to implement the State Plan. The State Plan will begin full implementation in July 1996. The funds will be used to:

1. Provide technical assistance via individual consultation to Utah's children and youth who are deaf-blind, their families, and their service providers.

2. Establish an extraordinary cost pool to assist local school districts to provide costly, specialized services which are deemed necessary and appropriate for an individual's IEP. These services may include, but are not limited to interveners, augmentative equipment, increased classroom assistance, and specialized instruction.

TRACES (Teaching Research Assistance to Children Experiencing Sensory Impairments) is funded through Cooperative Agreement No. HO25C30001 by the U.S. Department of Special Education, OSERS, Special Education Programs. The opinions and policies expressed by TRACES do not necessarily reflect those of the U.S. Department of Education.



Last Call

In the Winter 1995/1996 of *Deaf-Blind Perspectives* there was a readership survey. Please return surveys by June 30, 1996. A summary of the results will be included in the next issue.

Internet Connections

The following projects are pleased to announce their World Wide Web sites. If your deaf-blind project has a site on the Web and you would like to announce it in *Deaf-Blind Perspectives*, contact Randy Klumph (klumphr@fstr.wosc.osshe.edu).

Deaf-Blind Perspectives
www.tr.wosc.osshe.edu/tr/dbp

Current issue online, previous issues (ascii) available via ftp.

TRACES Project Home Page
www.tr.wosc.osshe.edu/traces

DB-LINK Home Page
www.tr.wosc.osshe.edu/dblink

Fact sheets, selected bibliographies, Family Resource Guide, and more.

Teaching Research Division Home Page
www.tr.wosc.osshe.edu

Contains e-mail links for Teaching Research faculty and staff and publications list.

STRIKE GOLD!

Hiring a person who is deaf-blind can be so rewarding . . . some might call it a golden opportunity

How would you like to find employees who can take on challenges that would overwhelm the average person? Employees who will be loyal to your company, dedicated to their jobs, and rarely miss a day at work? If so, call us at the Helen Keller National Center at **1-800-255-0411, ext. 270**. We'll be happy to tell you about the impressive achievements of competent, qualified employees who just happen to be deaf-blind.

Share Helen Keller's Vision

Helen Keller National Center for Deaf-Blind Youths and Adults*
111 Middle Neck Road, Sands Point, NY 11050

Regional Offices: Atlanta Boston Chicago Dallas Denver Kansas City Los Angeles New York Seattle Washington, DC

*Operated by Helen Keller Services for the Blind

Design: GTFH, 114 Fifth Avenue, New York NY 10011

Deaf-Blind Perspectives

- ❑ I enjoyed this issue of *Deaf-Blind Perspectives* but I am not on your mailing list. Please send future issues to the address below.
- ❑ I've moved! Please send future issues of *Deaf-Blind Perspectives* to my current address.
- ❑ I'm buried in interesting publications! Please remove my name from your mailing list.

Name: _____ Agency: _____

Street: _____ City: _____ State: ____ Zip: _____

Comments _____

_____

_____

Mark appropriate categories (3 max.)

- ❑ Person or parent of person who is disabled
- ❑ Special education (*e.g.*, teacher, aide)
- ❑ Administration (*e.g.*, Dept. of Ed., project director)
- ❑ Service provider (*e.g.*, social worker, group home)
- ❑ Technical assistance provider
- ❑ Higher education teacher/researcher
- ❑ Regular education (non Spec.-Ed.)
- ❑ Therapist (*e.g.*, OT/PT/speech)
- ❑ Teacher trainer
- ❑ Government personnel
- ❑ Medical professional
- ❑ Other _____

Please send my copy in:

- ❑ Grade 2 braille
- ❑ Large print
- ❑ Standard print
- ❑ ASCII

Mail to: *Deaf-Blind Perspectives* • Teaching Research Division • 345 N. Monmouth Ave. • Monmouth, OR 97361 • or call Randy Klumph (503) 838-8885, TTY (503) 838-8821, fax: (503) 838-8150, E-mail: klumphr@fstr.wosc.osshe.edu

All issues of Deaf-Blind Perspectives are available on the Internet at **www.tr.wosc.osshe.edu/tr/dbp** 0596

Deaf-Blind Perspectives is a free publication, published three times a year by the Teaching Research Division of Western Oregon State College. The positions expressed in this newsletter are those of the author(s) and do not necessarily reflect the position of the Teaching Research Division or the U.S. Department of Education.

Deaf-Blind Perspectives
Teaching Research Division
Western Oregon State College
345 N. Monmouth Ave.
Monmouth, OR 97361

Forwarding & Return Postage Guaranteed,
Address Correction Requested

Non-Profit Organization
U.S. Postage
PAID
Permit No. 344
Salem, OR

BEST COPY AVAILABLE